

Novel sociological methods and practices of engagement across disability communities

Edited by

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Novel sociological methods and practices of engagement across disability communities

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Editorial: Novel sociological methods and practices of engagement across disability communities

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KEYWORDS

disability, wellbeing, community engagement, qualitative research methods, disability studies, Mad studies, participatory approaches, ableism

Editorial on the Research Topic

[Novel sociological methods and practices of engagement across disability communities](#)

We intentionally chose a magnified photograph of a broken bone as the featured image for this Research Topic. We take up this image metaphorically, rather than as a direct reference to orthopedic medicine. Broken bones carried many meanings in relation to our thinking through the meeting places of medical sociology, disability studies and sociology of disability, and the fractures that remain between these disciplines. The immediacy of a broken bone recalled the efforts in the broad and contested field of disability studies to center the body/mind and bring impairment into the frame alongside its mobilization against ableism, within and beyond the academy. Bones are referred to in “Skin, tooth and bone,” the disability justice primer written by the foundational group ([Sins Invalid, 2019](#)), signaling the centrality of social movements as backbones and visionaries of crip futures. This image of the bone also alludes to “breaking open the bone” of mad grief and the growing presence of Mad studies as its own emerging field ([Poole and Ward, 2013](#); [Willer et al., 2021](#)). Lastly, in looking close-up at a fractured bone, we are reminded of the corporeality that connects us and the importance of scale and perspective for framing our understanding of social phenomena.

This Research Topic is woven together across many points of convergence, though three themes stand out: (1) disabled world making, (2) communities of care for longstanding wellbeing, and (3) novel research methods. By disabled world making, we mean how disabled people make and remake their worlds: in arts, cultural practices, through activism, and more. Many of these studies highlighted the skills, knowledge-practices and resilience of disabled people. Bringing many theories into dialogue, [da Silva et al.](#) challenge reductionist ideas of disability. They propose a complexity paradigm to understand disability as characteristic of human diversity, rather than deviation or pathology. [Landry](#) documents mad people’s world making, specifically consumer/survivor led businesses that were created in the 1980s and 1990s to counter their

exclusion from the mainstream labor market. Her work accounts for these small businesses as significant sites of mad people's advocacy in Ontario, where activist knowledge-practices were fostered through community organizing. Padilla and Tan present us with an innovative decolonial methodology that disrupts disciplinary boundaries and offer two gnosis-based, embodied counter-stories. These stories defy traditional epistemologies and embrace the diverse forms of knowledge and emotional production that disability can generate. Soldatic et al. employ participatory approaches, including the co-creation of AI-generated e-books, to study the important role of everyday technologies among culturally and linguistically diverse (CaLD) migrants with disabilities in remaking their worlds as new communities. The study highlights not only the barriers and burden CaLD migrants with disabilities experience but also, emphasizes participants' agency and creativity in navigating digital spaces.

The second thread, communities of care for longstanding wellbeing, refers to a whole host of community practices of wellbeing and care. Research within these texts amplified lessons from crip and mad kinship on keeping each other well. Here interdependence is both a reality and an aspiration. We found commonality across research that distilled shared and mutually constitutive practices of wellbeing, generating new insights and potential alliances that are necessary to build, mobilize, and sustain crosscutting communities of wellbeing. Ellis et al. write transparently about the first year of their 5-year co-produced research study, *Crippling Breath*, and the care-full work they undertake to ensure their research practices reflect the ethics and purpose of the project. This care extends to think through crip time, embrace slow scholarship, compensate community researchers and talk explicitly about grief, loss, and legacy in research processes. From a caregiver perspective, Ke shares lessons drawn from her experience of caring for her sister who has critical brain injuries. Ke uses a phenomenological approach to push back against ableist ideas of disability as deficit or a thing to overcome, and instead supports her sister's recovery by attuning to their current lived reality, to honor the changed condition of their body/mind. Middelman's reflections on the connections between ethics, methods and values in public space research over several years in Johannesburg lead him to conclude that reciprocal practices of wellbeing require internal shifts toward others as well as interdependence and collaboration across difference. Lastly, Yephthomi et al. introduce us to Indigenous approaches to mental distress among northeast Indian Naga communities, arguing Indigenous epistemologies recognize healing as a collective process.

Lastly, and in speaking most directly to the Research Topic's central call, several articles recounted novel sociological research methodologies and methods. Rooted in disability, crip and mad research praxis, they emphasize the importance of a strong commitment to accessibility that supports meaningful engagement and knowledge co-production with disability communities. Taking up and taking in disability theory in research practices and community engagement, as these authors suggest, requires creativity, shifting temporalities and technological innovation. For example, Beesley revisits the crucial role of Emancipatory Disability Research (EDR), critically analyzing its impact, possibilities and features that remain necessary for an anti-ableist praxis, while expanding its canon. What should be preserved from

EDR, he argues, is an emphasis on "*empowering subjects and its democratization of research practice*." Ryan centers joy in disability research and highlights the disruptive potential of bringing a crip "joyful" approach to narrative research. Narrative portraiture is presented as a participant-centered method that can produce nuanced counternarratives of siblinghood and disability. Sinclair thinks with Mad Time and its potential to disrupt normative and sanist research practices. She points to the violence produced by conventional methodologies which reproduce psychiatric relations and proposes the generative opportunities of Mad Time to be a subversive alternative approach. Wechuli considers what it means to crip ethnographic research as an emancipatory reorientation, including autoethnography and its subgenre evocative autoethnography. Wechuli's work aligns with others in the Research Topic, in terms of affective relations of crip time and resistance to disablism, ableism, and sanism in academia. Though we center these three threads across projects, we invite you to locate other points of connection and contention, as you make your way through this Research Topic of empirical and analytic papers.

Author contributions

DL: Conceptualization, Project administration, Supervision, Writing – original draft, Writing – review & editing. TM: Conceptualization, Project administration, Writing – review & editing. RA: Project administration, Writing – review & editing. HM: Project administration, Writing – review & editing. KS: Project administration, Writing – review & editing, Conceptualization.

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A family caregiver perspective: rethinking recovery with phenomenology

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Our phenomenal experience of the world is shaped by lived moments of the present, which not only sediment into the fabric of our current reality but also actively contribute to shaping it. We continually engage in the generative and rich making of life through this ongoing, dynamic interaction with the world. From this perspective, body–mind differences resulting from brain injury could be seen as a profound transformation of one's phenomenal experience of the world. The lessons I have drawn from my caregiving experience with my sister who has critical brain injuries highlight the need to move away from ableist beliefs that disabilities are deficits to be corrected or rejected to a positive and generative search for the new, alternative ways of living well with shifted physio-psychological conditions. Using phenomenological perspectives, I aim to shift the understanding of “abnormality” from the binary of normal/abnormal to a broader vision of care. For family caregivers who struggle to help their loved one to return to a better state of health and life quality, the key point of participating in the recovery process is to gear into the lived experience of the care recipient and grasp a genuine understanding of their reality.

KEYWORDS

phenomenological experience, family caregiver, social roles, body–mind, care

Introduction

My sister experienced a hemorrhagic stroke in 2019 and was placed in ICU for further observation after receiving a craniotomy. Years later, she is still diagnosed as having six types of disorders, including movement and cognitive disorder. Though with constant reminding she seems able to acknowledge her roles as mother, wife, sister, and daughter, she does so without any sense of actual commitment to them. Her previous understanding of herself and the world, as well as the relation between the two, seems to have been disrupted by the change in her bodily condition. Her ability to hold on to her previous social roles and fulfil the norms expected of her has also been largely hampered due to brain injury. She cannot connect to the world and the people around her in the same way. The disruption manifests in her impeded capacity to anchor meanings from her past to inform her present. From a phenomenological perspective, she has undergone a profound change in her way of being and her ways of experiencing the world. The way she situates herself in relation to others has changed.

More often than not, my sister is addressed as a patient even when she returns home. Although her surgery was performed and the wound was closed, the disease remains. As [Canguilhem \(1978\)](#) would agree, this judgment has more to do with self-appraisal and the dominant ideas of society than merely physician's opinions. Disability shapes an individual's relationship with their environment and the broader socio-cultural context in which they live, situating people in unique worlds that, while different, remain part of the larger shared world with able-bodied individuals. This interconnectedness highlights the intersection of personal and social experiences of disability, where both disabled and able-bodied identities are shaped

and intertwined. Writing about disability, therefore, is not merely an act of storytelling but an ethical and communal responsibility. It creates space to amplify marginalized voices and critique the social systems that perpetuate exclusion and oppression (Price, 2011; Siebers, 2008). Through this lens, disability is not just a condition but a politicized identity that challenges historical and cultural meanings ascribed to it (Garland-Thomson, 1997; Kafer, 2013). Writing about disability, particularly from the perspective of a caregiver, becomes an ethical engagement of transcending oppressive binaries.

In this light, instead of seeing my sister's disconnection/nonconformity to her previous social role as a failure, I will reassess her reality with a broader vision provided by phenomenology, in which the understanding of "abnormality" stemming from binary thinking is interrogated. The interrogation then opens up a search for new, alternative way for the person and their community to live. Drawing upon Merleau-Ponty's (2012) work, *Phenomenology of Perception*, I will explore the phenomenological constitution of experience, meaning the way experiences are structured and informed by phenomenological insights. One particular focus is on the latent content of experience that encompasses the sedimented past and the spontaneous embodied interaction with the present. This perspective will show how social and cultural specificity, as well as bodily conditions, shape one's phenomenal experience of the world. Ultimately, caregivers should engage in a search for "conditions of possibilities" (Messas et al., 2018) that would genuinely support the care recipients in their unique circumstance and lived reality, rather than attempting to suppress or homogenize their experience. By reflecting on my subjective experience of encountering my sister as a newly disabled body-mind subject through a phenomenological perspective, I intend to reconcile my anxiety as a family caregiver and her shifted psycho-physiological state.

The phenomenological constitution of experience

In Merleau-Ponty, there is a central focus on the body as the primary means through which we experience and engage with the world. The body as an anonymous, shared cultural body arises from the deep intertwining of individual embodiment and cultural context. It is not just a passive object but an active perceiving subject that intends, desires and acts in the world. A newly disabled body, as my sister is currently living with, inevitably constrains the subject's bodily autonomy to engage with the surrounding world as they did in the past, thereby placing them in an unfamiliar territory that requires a reunification of movements, senses and ideas. This process entails a transformation in the perception of the *Other-for-me*, in Sartre's (1943, p. 343) words. Here, the body is not only a personal experience but also an object in the social realm as seen and experienced from the perspective of the Other.

The initial step, acceptance rather than resistance, is of utmost importance, as I learnt through my caregiving experience with my sister. We are often perceived in roles dictated by normative expectations, which prescribe certain traits for how people should behave within those roles. In the urban China context, especially in a metropolis like Shenzhen where my sister lives, there is an intensifying demand on mothers to become more knowledgeable and skillful in providing care to their families, particularly in regard to child

development and parenting (Zhang et al., 2023; Wang et al., 2024). For example, engaging school-age children in various extracurricular activities such as English and piano classes is considered an essential aspect of good motherhood (Meng, 2020). As a mother, my sister's ability fulfill these expectations was not just a personal achievement but a marker of social belonging. After her brain injury, however, her inability to maintain these traits caused us, as her caregivers, discomfort and a compulsion to guide her back on track. This discomfort stemmed from an ingrained fear that her divergence from these norms would render her marginalized in the eyes of society, which tends to judge individuals, especially mothers, against rigid standards of productivity and care.

My sister underwent early rehabilitation involving cognitive, linguistic, motor, and swallowing therapies, supplemented by acupuncture and electrotherapy. In this process, we often felt frustrated by the lack of steady progress, especially when her emotional fluctuations disrupted treatments. Her significant muscle tension, impeding limb recovery, felt like obstacles rather than integral parts of her healing, leading to frequent misunderstandings and frustrations. However, a reflective approach revealed that we had prioritized a return to "normalcy" over my sister's subjective and nuanced experience, and that her differences, brought out by her new reality, were not adequately considered or accommodated in the rehabilitation setting as we prioritized conventional measurable outcomes over exploring a unique recovery path tailored to her changed conditions. Moving forward, it is crucial to understand the implications of being seen as "deviant" from conformist expectations of the "normal," and how that affects our choices and goals in assisting our disabled loved ones. Embracing a broader perspective on disability and differences can be both empowering and challenging.

The norms of body

As my sister becomes incapable of fulfilling any of her previous social roles in her new body-mind conditions, she is no longer seen as a productive member of the society, and thus becomes susceptible to being devalued, objectified, or rejected as a burden. Dosanjh et al. (2021, p. 336) also observed divergent copings with long-term FMD symptoms; some people continued to suffer stress, shame, and anxiety, or mourned their loss, while others "were able to value themselves in new, albeit more limited, roles" after a period of adjustment. Although a disabled body can have severe consequences on individual wellbeing and health (e.g., dissolution of instrumental social relationships and bonds that leads to social isolation), it is not inherently harmful to develop and maintain a meaningful life and identity. Individuals are not passive recipients subject to the reward-punishment mechanisms of social systems. The body of my sister is subject to value judgment of the society.

However, the dependency of the subject's meaning-making on social norms is only threatening if we predicate the notion of subjectivity on the ideal of a self-possessed sovereign subject (Oliver, 2001). By embracing an interrelational perspective of subjectivity and acknowledging the profound effect of social relationships on one's sense of self and agency, "dependence is seen as the force of life, as the very possibility of change," as opposing to a one-way drive to violence and death (68). Such a view of dependency is upheld with Levinasian ethics, that relations to the other entails ethical responsibilities, where

justice emerges. In her later work, [Oliver \(2004, p. 199\)](#) is more explicit, stating that “ethics is the acknowledgment that we are by virtue of response from others and by virtue of response from meaning through which we become beings who mean. Subjectivity, then, is inherently ethical. We are subjects or subjectivity only through our relations with others, and ultimately with otherness.” Although our subjective experiences and social relationships are predominantly shaped by the overarching social system that imposes distinctions and exclusions, a change in one’s social identity—such as becoming disabled—offers an opportunity to reevaluate how we interpret and respond to social interactions. In my sister’s case, her psychic space is to be reimagined within the confines of her shifted physical circumstances and reduced social connections. For the family caregivers, we become aware of our unconscious hostility to difference or deviance from the unquestioned norms, as we witness the challenges and injustices faced by our loved ones who have become disabled: we were once shut out of the elevator because moving my sister in her wheelchair made us too slow for impatient passengers; my five-year-old niece, my sister’s second child, cried out of boredom at home because her mother was always sedentary and inert; and my mother kept mourning why my sister still had not regained her “consciousness,” in the sense of being aware of who she used to be. The individuality within the new conditions is ignored. And this is a critical point concerning why overcoming does not work, why diagnosis obscures more than it reveals, and why cure tends to essentialize the reality rather than provide a holistic approach to who we are and what we need in order to lead meaningful lives with the changed body–mind conditions. Recognizing the newfound individuality asks for not only individual perspective shifts but also broader changes in social perception and attitudes that maintain the power of the ableist framework.

The new understanding

Once I embraced a phenomenological understanding of how to approach my sister’s changes, I began to recognize and give meaning to her potential within these new circumstances. I realized that she has other possibilities beyond those defined by societal norms and expectations, which are no less significant for her and the community than her previous ones. For example, while she may not exhibit a proactive preference for exploring her environment, she shows interest when prompted, such as when asked if she wants to visit the kitchen. Once in the kitchen, she expresses curiosity and finds enjoyment in the new surroundings, particularly when guided to observe specific elements like plants. This indicates that with intentional guidance, she can form temporary connections with her environment. Additionally, as her mobility improved, she exhibited some agency, demonstrating that her potential for engagement and interaction with her surroundings can be activated and nurtured. As [Oliver](#) stresses, we are not only responsible for our fears, desires, and emotional expressions, but also for their effects on others, “we are responsible for the other’s response.” (199) This acknowledgement of the ethical responsibilities to others is the departing point where we “forgive,” or in other words, embrace the uniqueness and individuality of others within the fabric of social coherence. My role as a family caregiver has afforded me an opportunity to conduct a “self-critical hermeneutics” that involves examining and questioning

my own ableist-centered perspectives regarding my sister’s changes. Reflecting on my previous emotions and desires, mostly anxiety and frustrations regarding the slow progress of my sister in reconstructing her mobile and cognitive capacities, I become more accepting of her conditions and changed my approach to meet within those limitations. Now, I choose to disregard what she cannot do and focus on what she can do. Through this shift in perspective, understanding and supporting my sister’s rehabilitation is no longer filled with a sense of urgency to bring her back to “normal,” especially as this direction is not only futile but counterproductive given the dramatic physical and mental alternations.

Ableism, according to [Campbell \(2009, p. 5\)](#), is a “conceptual tool... a chief feature of an ableist viewpoint is a belief that impairment or disability (irrespective of ‘type’) is inherently negative, and should the opportunity present itself, be ameliorated, cured, or indeed eliminated.” Failure to meet the normative standards is seen as “deviance” from what is generally accepted as normal or the norm. [Clare \(2017, p. 8\)](#) warns, “[that] disabled people can only succeed by overcoming disability is an ableist cliché.” The fear that my sister will be devalued and excluded from society due to her disabilities dominated my approach to her new reality; I failed to understand her needs and provide her with adequate support. Unable to access my sister’s world, I imposed goals on her, hoping we could “step-by-step,” “gradually and quantitatively,” “effectively,” overcome her deficits and aid her once again in becoming able-bodied. My demands to correct the perceived pity and wrongness of my sister’s disability have been conditioned by my able-bodied perspective and the internalized ableist norms that our society perpetuates. “The common narrative that we endorse is ‘overcoming,’ which is filled with “unjust ability expectations determining how bodies should be in the very recesses of how they are” ([Reynolds, 2019, p. 5](#)). The concept reduces disabilities to merely functional defects in the physical and/or mental realm and disregards the vitality of differences of body–mind manifestations, assuming that the located problems can be fixed, contained, or eradicated.

Discussion

My reflection on my sister’s actions, speech, and affections points to the need for unlearning the learned, unknowing the known, and undoing thoughts structured by habit, custom, rules, and other social constructs. In my personal experience, the relationship between disabled people and caregivers is often characterized by independence and involves power imbalances leading to mistreatment and exploitation of the person receiving care, which can occur across settings, from home-based caregiving arrangements to hospitals. However, in light of evolving scholarship, this dynamic has been critically reimagined through more relational and reciprocal models of care. [Bellacasa \(2017\)](#) compels us to consider “the meanings of care as a noninnocent but necessary ethos of always situated implications” (p. 24), emphasizing care as a way of knowing and thinking connectedly—about humans, nonhumans, and the systems that entangle us. Similarly, [Nishida \(2022\)](#) advocates for moving beyond a dichotomized understanding of care to embrace it as a situated practice, deeply attuned to the particularities and complexities of another’s existence. This reconceptualization shifts care from being a set of prescribed actions or outcomes to an empathetic and adaptive

practice that honors the changed body–mind conditions of the care recipient, as in my sister’s case.

When I set aside goals based on the dominant norms of our ableist society and stop assuming that my sister can be restored to her former self, the recovery process transforms. It becomes a journey searching for day-to-day approaches attuned to her shifted subjective experience of the world. I shift my focus from major milestones to celebrating small achievements, such as her managing to do one or two more leg lifts than in the previous session. Whenever she made even minor progress, I cheered her on, which clearly brought her joy. This perspective not only aids my sister in her functional recovery but also encourages her to discover new ways of being and interacting with the world. The tension between homogenizing for standards and accommodating the individual can thus be eased with an extensive vision of returning to health. As Clare (2017, pp. 14–15) points out, the essence of restoration is to understand and align knowledge, experience and expectation with the unique rhythms of the new conditions; it is “a fluid, responsive process...requires digging into the past, stretching toward the future, working hard in the present. And the end results rarely, if ever, match the original state.” For family caregivers, engaging deeply with the care recipient’s lived experience is essential to help them find meaningful ways to thrive within their physical and mental limitations. My own caregiving journey has provided a valuable opportunity to reflect on how conventional understandings of disability, cast in the ableist logic, can shape our approaches and attitudes. This reflection entails broader implications for both clinical and social contexts. It underscores the importance of fostering not only individualized but also deeply empathetic healthcare philosophies and practices that attune to the unique contexts of each patient. Socially, it challenges and encourages a paradigm shift in public perceptions, seeking to build greater inclusivity and a more compassionate society where differences are not just accommodated but valued.

Conclusion

My conceptual reflection on my caregiving experience of my sister starts from my pondering on what it means for her to be disconnected from her previous social roles. Fulfilling one’s social roles is essential for one to be properly accepted and positioned in social relations, which also delimits personal attitudes and choices. Body–mind differences resulting from brain injury could be seen as a profound transformation of one’s phenomenal experience of the world. The lessons I have drawn from my caregiving experience highlight the need to move away from ableist beliefs that disabilities are deficits to be corrected or rejected to a positive and generative search for the ideal ways of living well with the shifted physio-mental conditions. For family caregivers who struggle to help their loved one to return to a better state of health and life quality, the key point of participating in the recovery process is to gear into the lived experience of the patient

and to grasp a genuine understanding of their reality. In this way, both the family caregiver and the patient are better off finding coexistence, if not consensus, of values and beliefs in the diverse forms of human bodily-being.

Data availability statement

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

Ethics statement

Written informed consent was obtained from the individual(s) for the publication of any potentially identifiable images or data included in this article.

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Narrative portraits: affirmative approaches to understanding learning disability in the everyday

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Narrative portraits provide an opportunity to uncover new affirmative understandings of disability and family through the focus on lived experiences. This article will explore how a critical disability studies lens helps us understand narrative approaches and the crip potentials of narrative portraits. Considering the 'joy deficit' within disability research this paper highlights the disruptive potential narrative portraits bring to family sociology and disability studies. This paper presents a narrative portrait as a case study, taken from research carried out with 14 siblings of people with learning disabilities from the UK. This is used to explore how siblings of people with learning disabilities understand disability in the everyday with a focus on the affirmative and disruptive counter-narrative nature of the portrait. Through this, the potential for counter-narratives within this methodology will be made clear with the unique nature of sibling relationships central to this. Narrative inquiry can challenge dominant deficit understandings of disability through narrative repair. Narrative portraits take this further through the focus on participants' words in longer extracts allowing their viewpoints to be centred. This approach lends itself to studies of the everyday through the space afforded for deeper, nuanced accounts of life. The approach crimps more classic narrative research methods through challenging normative understandings of the researcher's role in favour of a more participant-centred approach to analysis. In doing so, there is potential to imagine a more inclusive scholarship. When addressed through a disability lens, narrative portraiture uncovers lived experiences of disability, how disability is navigated in families, and how siblings negotiate disability in their relationships allowing the nuances of everyday experiences of disability to arise.

KEYWORDS

learning disability, narrative portraits, everyday sociology, qualitative research, narrative inquiry

Introduction

Narrative portraits offer the potential to generate new affirmative understandings of disability and family through the focus on lived experiences. By centring the participants' own words, with a particular consideration to context, portraiture allows for counter-narratives to emerge clearly. Drawing on narrative inquiry, portraiture sees research data presented in a way that gives the audience insights into participants' narratives through extended sections of their own words that are brought together by the researcher with the aim of both respecting their narrative and addressing research aims (Rodríguez-Dorans, 2022). This paper draws on one narrative portrait as a case study to make clear the affirmative potential of narrative portraiture in understanding learning disability in the everyday.

Sibling relationships are nuanced and complex (Davies, 2023); they can be characterised by both loving and caring feelings as well as more frustrating and at times conflictual ones

(Davies, 2015). Disabled people are not always afforded this nuance in research around siblinghood and disability, which leads to commonplace deficit narratives being reproduced through a focus on non-disabled sibling outcomes (see Meltzer and Kramer, 2016 and Ryan, 2024 for overviews). When considering the need for affirmative learning disability and siblinghood research, Shuster and Westbrook's (2022) conceptualisation of 'joy deficit' offers a clear argument for the importance of challenging commonplace deficit narratives in research around marginalized communities. They argue that due to the focus on social harms in much of social science, research outputs inevitably contribute to understandings of marginalized communities that are centred around harms and, as a result, deficit. This then influences understandings of lived experiences socially and culturally leading to deficit narratives being commonplace within society. The authors call for more research that acknowledges joy, an argument that has been applied to disability studies research specifically (Sunderland et al., 2009) with this paper working to contribute to understandings of learning disability and family that allow joy to be a central part of relationships. Narrative portraits are one way to achieve this through their potential for 'more detailed, descriptive, and richer narratives that reveal more of the identity and interests of participants and researchers' (Smyth and McInerney, 2013: 4).

Drawing on a wider research project exploring the experiences of siblings of people with learning disabilities, this article will make clear the potential of narrative portraiture in presenting counter-narratives that challenge dominant understandings of siblinghood and disability. This will be achieved through an introduction to debates within siblinghood and learning disability research, highlighting the importance of counter-narratives. Following this, the concept of narrative repair and the affirmative potential this brings (Lindemann, 2001) will be discussed. Narrative portraiture will then be explored, with reference to analysing and creating portraits, which leads to the methodology of this paper. Toby's narrative portrait is then presented, which explores his relationship with his sister Beth through their love of playing video games together and how this has changed as they have grown older and Toby has moved away. The portrait is analysed following the Labovian-influenced (Labov and Waletzky, 1997) approach advocated by Rodríguez-Dorans (2022) with particular attention on the affirmative aspects of Toby's narrative.

Thinking about siblinghood in the everyday

Being a sibling is a unique relationship, often cited as one of the longest people will have in their lifetime (Allan, 1979), navigating a number of changes over this time. Siblings can be a great support in times that are difficult and in other moments frustrating and conflictual. We tend to understand these feelings, even the more aggressive ones, as to be expected from siblings, especially in childhood (Davies, 2023). Davies (2015) refers to the 'emotional tightrope' that characterises sibling relationships as almost simultaneously loving and more visceral. These understandings are rooted in the mundane everyday experiences of growing up together, with this leading to moments of closeness and love but also sometimes conflict and frustration. This is seen in Morgan's (2011) conceptualisation of 'family practices' which is rooted within the everyday 'both in the sense of those life events which are experienced by a significant proportion of any population (partnering, parenting,

sickness, bereavement) and, equally, those activities which seem unremarkable' (Morgan, 2011: 6). Punch (2008) reflects on the nature of sibling relationships drawing on Goffman's (1969) dramaturgical metaphor to place siblinghood as a 'backstage' relationship leading to siblings engaging 'in a backstage informal presentation of self without fear of the consequences of putting on an unpolished performance' (ibid: 341). Furthermore, Davies (2023) refers to 'living alongside' to capture the everyday-ness of sibling relationships with a particular focus on the heightened proximity and intimacy this brings. This context highlights the importance of nuance in how we analyse sibling relationships, with there being a need for recognition of the ups and downs that are to be expected of growing up alongside one another.

When considering siblinghood and disability, it is important to acknowledge how research exploring this has often reproduced deficit understandings. Meltzer (2018) reflects on this, arguing 'sibling disability research has traditionally defined the relationships between siblings where one has a disability by what they are not—that is, when compared to the normative view of relationships between siblings where neither have a disability, sibling relationships that include a person with a disability have traditionally been found wanting or damaged in comparison' (Meltzer, 2018: 1228). This presentation often draws upon understandings of disability as deviation from the 'ideal type' (Garland-Thomson, 2007). This will be revisited further into the paper. In response to presentations of 'wanting' or 'damaged' sibling relationships, Meltzer (2018) argues for a more nuanced reading of disability and siblinghood. The importance of allowing for this nuance when exploring siblinghood and learning disability has been highlighted in previous research. For example, in the study by Cebula et al. (2024) about the experiences of siblings of people with Williams syndrome, they note the closeness and warmth of the relationships and call for more research that approaches sibling relationships in a more holistic manner. Similarly, research by Stalker and Connors (2004) with siblings of people with learning disabilities challenges pathological narratives in favour of reflections of the everyday that echo wider family and sibling research. Moran-Morbey et al. (2024) further highlight the importance of recognising the structural factors at play, and how these must be part of how we understand the experiences of siblings to ensure we move away from individualising, pathological narratives of disability being reproduced. These examples present an articulation of siblinghood that is more in line with wider family sociology understandings as nuanced and complex.

Narrative inquiry and disability studies

Narrative inquiry offers a path towards more holistic understandings of disability and siblinghood through focusing on longer periods and more in-depth data allowing for nuances to come through more clearly. For Wells (2011), narrative inquiry is interested in looking at language as opposed to 'through it'. To achieve this, researchers must explore how a story unfolds over time, the performance of the narrative, narrative structure, its reception, and the cultural contexts in which it is based. Narratives can be understood in a number of ways, including "folk theories, 'frames', 'scripts', 'mental models', 'cultural models', 'discourse models', 'social models', and 'figured worlds'" (Gee, 2005: 89). For Frank (2010), narratives are best understood as stories, something they argue researchers should embrace. Stories are a key part of how we create meaning

(Thavakugathasalingam and Schwind, 2022); indeed, Gubrium and Holstein (2009) argue that narrative practices are how we bring meaning to experiences. This framing recognises that narratives can only be effective if they are understood by their audience. This is commonplace in narrative inquiry reflections; for example, Freeman (2007) notes how stories, whilst expressed by 'a self', are made with others through discussion. Wells (2011) builds on this stating that narratives are informed by context, audience, and culturally specific understandings amongst other things, something that must be recognised in analysis. This recognition of narratives as needing to be understood by their audiences is taken further by Sparkes and Smith (2011) who use the phrase 'conventions of reportage' to refer to the importance of drawing upon socially sanctioned viewpoints or risk people not understanding a narrative. They build on Medved and Brockmeier's understanding of narrative as fitting within a 'generalised and culturally established canon' (Medved and Brockmeier, 2008: 469).

Within this framework, we begin to see the potential questions that can arise when an individual's narrative does not coincide with this 'culturally established canon' (Medved and Brockmeier, 2008: 469) and the work that can go into attempting to fit within these boundaries. Where narratives are seen to create meaning, we see the power that narratives have to influence how disabled people are understood culturally, with examples such as the study by Grue (2016) on inspiration porn and Jarrett's (2020) exploration of understandings of learning disability historically highlighting the damaging nature of popular narratives of disability. Sparkes and Smith (2011) go on to note the implications of not fitting it, noting that 'stimulating narrative imagination' works to 'achieve solidarity and bond with others empathetically as fellow human beings' (ibid: 369). From this, we can see how narrative links to understandings of marginalised experiences with the space afforded by a narrative approach to lived experience and commitment to the whole bringing with it the potential for counternarratives to be generated (Solórzano and Yosso, 2002), something that will be explored in further into the paper.

Narrative methodology brings with it questions of validity and narrative truth. Narrative portraiture is by no means immune from this discussion and leans into the role of 'narrative truth' in how we understand narratives as data. The question of validity in narrative research is one that is framed around 'truths', with Polkinghorne (2007) arguing 'the language description given by participants of their experienced meaning is not a mirrored reflection of this meaning' (ibid: 480). Spence (1982) refers to 'narrative truths', with Kalekin-Fishman (2016) building on this with the term 'lived truths'. On the question of 'truth' in narrative research, Lieblich et al. (1998) argue "stories are usually constructed around a core of facts or life events, yet allow a wide periphery for the freedom of individuality and creativity in selection, addition to, emphasis on and interpretation of these 'remembered facts'" (ibid: 8). Returning to portraits specifically, and to the study by Rodríguez-Dorans (2022) which argues 'portraits and the narratives that accompany them do not intend to present accurate realities, they are interpretations that aim to reflect people's narrated experiences' (Rodríguez-Dorans, 2022:80). This understanding of 'narrated experience' returns to conceptualisations of narrative as being central to how we create meaning (Hoffman, 1993; Thavakugathasalingam and Schwind, 2022), a sentiment captured in Garland-Thomson's (2007) reflection 'narratives do cultural work. They frame our understandings of raw, unorganised

experience giving it coherent meaning and make it accessible to us through story' (ibid: 122).

Narrative repair and affirmative research

Counter-narrative research has its origins in critical race theory (Solórzano and Yosso, 2002) and works to challenge dominant majoritarian narratives through centring alternative perspectives (Klinge et al., 2020). Lived experiences, often from marginalised perspectives, are one of the key aspects of counternarratives (Delgado, 1984; Walker et al., 2020). For hooks (1994), counter-narratives are sites of resistances, as captured by Mohanty's (1989) argument that 'resistance lies in self-conscious engagement with dominant, normative discourses and representations and in the active creation of oppositional analytic and cultural spaces' (ibid: 185). Nelson (2001) argues identities are constituted through narratives and in some instances subsequently damaged through this process. They argue counter-narratives act as a means to carry out 'narrative-repair'. This process sees the damaged narrative replaced by more representative ones through the centring of counter-narratives.

This understanding places counter-narratives as radical spaces of resistance against dominant perceptions. Dominant understandings of learning disabilities often reinforce pathological, deficit-based understandings, and a counter-narrative approach provides an opportunity to challenge this. Leaning and Adderley (2016) refer to 'problem-saturated narratives' as commonplace in the understandings of disability. Garland-Thomson (2007) captures the role of narrative in how we understand disability culturally:

'Both our bodies and stories we tell about them are shaped to conform to a standard model of human form and function that is called normal in medical-scientific discourse, average in consumer capitalism and ordinary in colloquial parlance.' (ibid: 114)

Garland-Thomson makes clear how narrative shapes understandings of disability, making the link between understandings of 'ideal types' and capitalism. The role of capitalism in shaping understandings of disability is well documented (see, e.g., McRuer, 2006; Oliver, 2013; Goodley and Lawthom, 2019). These narratives are often situated in medicalised understandings of ideal types, a topic that has been the subject of much criticism in critical disability studies (Kittay, 2001; Berlant, 2007; Kafer, 2021). These narratives place disability as the antithesis of ability, with this bringing with it an understanding of 'lack'. Outlining 'crip theory', McRuer (2006) calls for 'counter-representations' that challenge these capitalist notions of bodies. McRuer challenges understanding of disability as lacking in favour of celebrating disability, a sentiment echoed in Goodey's (2016) work on inclusion phobia. Goodey (2016) draws a distinction between alternative norms and abnormal stating 'there is of course another way of looking at difference, we could celebrate it, as diversity' (ibid: 55).

Focusing on lived experiences acts as a way to challenge medicalised narratives. For example, in his research about parents of children with learning disabilities, Thomas (2024) reflects on how participants actively challenged deficit understandings of parenting a child with learning disabilities. Working in direct contrast to dominant narratives, counter-narratives are 'stories that lie in tension with the

ones that we are socialised to expect' (Andrews et al., 2004: 97). Returning to Shuster and Westbrook's conceptualisation of 'joy deficit', it has been levelled at disability studies that there is a lack of joy in research (Sunderland et al., 2009). This literature review has pointed to deficit-informed understandings of siblinghood and learning disabilities that are commonplace in the field. In the context of this joy deficit in disability studies, research into lived experience that allows space for joy can contribute to narrative repair regarding people with learning disabilities and siblinghood. Narrative portraiture offers insight into lived experience and space for participant stories to be presented, with nuance, in their own words.

Narrative portraiture

Narrative portraiture is a method of presenting data which centres participant voices with an extended extract presented from the participants' words. This paper draws on the approach to portraiture outlined by Rodríguez-Dorans (2022) in the book *Narrative Portraits in Qualitative Research*. Rodríguez-Dorans identifies affects, first-person narratives, and 'close up storytelling' as core features of narrative portraits with the goal being one of creating 'a glimpse into the participants lives which is simultaneously deep, succinct and evocative' (ibid: 13). To do this, participants' words are brought together to create a portrait that gives insight into their experiences through the frame of the focus of the research project. The portraits can stand on their own with there often being a clear narrative throughout. This approach echoes wider narrative inquiry through considerations of context and of bridging the gap between personal experiences and the cultural factors that inform them (Crouch and McKenzie, 2006).

Rodríguez-Dorans (2022) advocates an adapted version of the Labovian approach to coding (Labov and Waletzky, 1997) in the formulation of narrative portraits, adding on some extra considerations more specifically focused on portraiture. This sees the researcher break down the analysis into different focus points, with these being encouraged as a guide for coding: characters, orientation in time, complicating action, result and evaluation, small stories, special narrative features and the abstract (Labov and Waletzky, 1997; Rodríguez-Dorans, 2022). Characters is interested in the key actors of the narrative, both those explicitly referenced and those who are implicit. Within this focus, we can begin to ask questions about who are the key figures in the story and who are they to the participant. Orientation in time sees the researcher looking for moments in the narrative that place it, both geographically and with respect to time and chronology. Complicating action refers to 'concrete situations that disrupt the sense of flow in the life of a participant' (Rodríguez-Dorans, 2022: 28); these can be major life events or more everyday changes that arise in the narrative as points of tension. Result and evaluation is interested in the outcomes of events in the narrative, both with regard to actual events and also from insights participants gain and reflect upon. Small stories is concerned with examples of stories within the wider narrative. These will be moments where participants tell of experiences that have distinct beginning and endpoints. Special narrative features look towards the themes of the narrative, here the coding would be interested in how the narrative speaks to the research focus. Finally, the abstract is concerned with the overall point of the narrative. In this focus, the narrative is approached more holistically

looking at what the narrative tells us and what points are being raised often. This focus on coding allows researchers to engage with participant data with the narrative in mind. In doing this, we get a sense of the story of their data which can then be used to inform a narrative portrait.

In creating a narrative portrait, the participant's words are brought together in a manner that creates a short story that gives insight into the narrative of their interview. This is not to say that all of the points of coding will be relevant to all narratives; instead, some may be more applicable than others. Through using this approach we are encouraged to produce narrative portraits that give an insight, in the participant's words, into their experiences that is comprehensive and respectful of their story as a whole. For Smyth and McInerney (2013), it is essential to recognise that the portrait is a product of the researcher and their research focus, arguing the process can be understood as 'using the informant's own words, all the while being continually mindful of the need to hold onto the essence of what we have isolated as being most prominent' (Smyth and McInerney, 2013: 17). Rodríguez-Dorans (2022) builds on this noting how through the act of creating a narrative portrait we make clear the argument of the narrative through piecing together extracts from the participant's transcript in a manner that makes 'a compelling story that lays the researcher's argument for the readers to see' (ibid: 42).

Rodríguez-Dorans (2022) highlights the link between narrative portraiture and counter-narrative research. This is done through recognition of the potential for the approach to centre marginalised experiences. They argue that for many marginalised groups, their identities are 'relegated to the fringes of significance' (ibid: 150), with portraiture offering the chance to make these experiences more central. Furthermore, when read alongside the understandings of damaged identities and calls for narrative repair (Lindemann, 2001), not only does a narrative portrait approach offer the chance to bring identities into the centre, but by doing so also offers new understandings driven by lived experiences. Narrative portraiture offers a chance to centre counter-narratives that are nuanced and human by extension. Smyth and McInerney (2013), for example, place portraits as advocacy ethnography with a focus on participant voice allowing for the disruption of the power imbalance that occurs between participant and researcher. For Rodríguez-Dorans (2022), the approach allows for more open dialogue and understanding to be reached between the reader and participants:

'Because when we are able to recognise ourselves in the individual, even if it feels far from our own reality, if we open ourselves to understand 'the other' in front of us, not as a research participant but as a sentient being, with drives, needs, and desires, we might be able to look at ourselves through their eyes and recognise ourselves in them.' (ibid: 140)

This extract captures the disruptive potential of the method. Furthermore, when read alongside the context of a joy deficit in disability studies and the need for more affirmative research there is an argument to be made for the counter-narrative potential of this research approach. Within disability studies, narrative portraits offer a chance to explore lived experiences of disabled people. This is seen in Jacobs et al.'s (2020) research into the transition from school to adult services for young people with learning disabilities. They bring together their narrative portraits from a wide set of data, including

interviews with family, service providers and observations in order to create narrative portraits for non-verbal participants. In doing this, they make clear the role of the researcher in constructing narrative portraits whilst also giving insight into everyday life as understood through the data. Connor (2008) produces portraits in their work on the intersection of learning disability, race and class with the aim of ‘creating a picture of how participants understand learning disability as part of their lives’ (ibid: 69). Connor uses the phrase ‘portraits in progress’ to capture the more fluid nature of the work produced, moving away from chronological reflections in favour of ‘asynchronous thoughts and memories’ that come together to offer insight into the research focus.

Methodology of study

This paper draws on an aspect of the research carried out for my PhD thesis. This research explores the experiences of siblings of people with learning disabilities with a focus on gathering holistic narratives of childhood. To do this, narrative interviews were conducted with 14 siblings of people with learning disabilities aged 18–32 years. Participants were asked to bring along a timeline of their childhood and some photographs to further encourage discussion. These interviews followed Rosenthal’s (2007) narrative framework, which sees the interview split into two sections. First, the participant is given the chance to provide a biographical narration in which they are asked to talk through their timeline with minimal researcher input. The second part of the interview followed a more conventional semi-structured approach with the interviewer asking follow-up questions with the intention of generating richer detail on parts of their narrative. Alongside this, there was a series of questions asking participants about their everyday life growing up that followed the theme of *what was the morning before school like in your house? What was dinnertime like growing up?* These questions worked to ensure that the minutiae of everyday family practices were explored in the interviews. Participants often covered these questions during their biographical narration, but having this set worked to make sure each participant discussed their everyday experiences in some form. The interviews were conducted either online or in-person depending on the preference of the participant. They were recorded and transcribed by myself prior to coding.

The addition of timeline mapping and photo elicitation worked to give participants more control of the interview away from the researcher. By bringing things to discuss, participants were able to shape the interview in a way that was distinct from the interviewer’s input (Mannay, 2010). Alongside this, a creative method element to the study acted to try to ensure comfort for participants in interviews that could have potentially been upsetting (Mason and Davies, 2009). The timeline mapping consisted of participants being asked to ‘bring in a timeline of your childhood’; this brief was deliberately loose and allowed a number of interpretations from those who took part. This varied from handwritten notes of key events and dates to in-depth PowerPoints which incorporated the photographs. The timelines worked as interview prompts, with analysis focusing on how participants discussed them. This was chosen in recognition of the ‘long biographical narration’ as something that is not easy to do. The timelines enabled participants to have notes with them and acted to guide their narration, further contributing to the comfortableness of the interview. The photo

elicitation acted similarly with the main role being one of encouraging discussion. Family photographs tend to be ones of joyful moments (Kuhn, 2002) and this meant that often the photographs helped provide comfort for the participants and give them a chance to discuss something more upbeat where necessary.

The transcripts were coded narratively, drawing on the Labovian framework (Labov and Waletzky, 1997) for narrative inquiry as outlined by Rodríguez-Dorans (2022). This required the data to be read with a focus on characters, orientation in time, complicating action, result and evaluation, small stories, special narrative features, and the abstract. Not all of these were relevant in each narrative meaning different portraits draw on these in different ways. The thematic analysis that ran alongside informed some of the narrative coding, particularly around special narrative features and the abstract, with common themes being a central focus in the construction of the portrait (Wells, 2011). In crafting the portrait, the participant’s words were not changed, but the researcher brought together discussion points with the aim of giving insight into how they featured over the course of the narrative. Drawing on Rodríguez-Dorans’s (2022) framework for creating narrative portraits, the excerpts are brought together in a manner that aims to create a ‘compelling story’ whilst making clear the arguments of the researcher with regard to the focus of the project.

It is important to recognise the role of the researcher in this project as well as the choice to interview non-disabled siblings. The project was inspired by my own experiences growing up with an autistic sibling with learning disabilities. As outlined by Meltzer and Kramer (2016) research into siblinghood and disability more widely often reproduces deficit narratives centred around outcomes for non-disabled siblings. This informed my decision to interview non-disabled siblings; however, it must be recognised that the viewpoint of the sibling with learning disabilities does not feature in the portrait. Considering research around “disability by association” (Burke, 2010; Scavarda, 2023), the narrative outlined in this study is not presented to replace those of people with learning disabilities; instead, it is offered with the hope of sitting alongside and contributing to narratives of siblinghood and learning disability that are generative and affirmative.

This paper draws on one narrative portrait as a case study to make clear the affirmative potential of narrative portraiture in understanding learning disability in the everyday. Toby’s portrait (pseudonym) was chosen as his narrative is one that highlights how the methodology can lead to more affirmative understandings of learning disability. Toby will be introduced along with his narrative portrait. This will be followed by the discussion in which the portrait will be analysed using the framework outlined in this section. Specific attention will be given to how Toby’s account of his childhood presented an affirmative counter-narrative of siblinghood and learning disability. The analysis will focus on the everyday experiences that the portrait captures, with particular attention paid to the role of the narrative coding framework as outlined above.

Toby’s narrative portrait

Toby’s narrative portrait focused on his experience of playing video games with his sister. This played a central role in his narrative,

with the games console the Nintendo Wii being afforded its own section of his timeline:

Nintendo Wii Brother obsessed. Bought on day it came out. Cannot remember when but she [Beth] got hooked on Wii Bowling. Our main time spent together at home throughout secondary school, will play some games after dinner or something.

In the interview itself, the Nintendo Wii was returned to throughout, with Toby describing fond memories of time spent playing with his siblings. The narrative portrait covers the role of the games console during childhood and then further into adulthood and the present. During these reflections, Toby touches on the importance of one-to-one time with his sister, his feelings about his parents, and the joy of playing together. To provide context for the portrait, Toby is in his late twenties and lives abroad as a teacher. He has two siblings, Josh, who is the eldest and then Beth, who is the youngest. Toby is from a white, middle-class family based in the North of England.

Toby's narrative portrait: "the best 1 on 1 time that I have with Beth is playing Wii sports together"

There's a special shout out to the Nintendo Wii there in the middle [of the timeline] because again, that's a huge part of our lives, with Beth's obsession with it I think we have like 5 Wii's at home so if one breaks we get a new one, I took one to uni and it's come back, we are stockpiling them at home it feels like. We got it on the day it came out because Josh was completely obsessed with it like for months before it came out coming into the bedroom like 'oh there's a new trailer for the new Nintendo Wii' saying 'we need to get this game and this game' you know, my parents probably just found it funny how obsessed with it he was and then they got really into it when we brought it but yeah I cannot remember at what point Beth got really into it but she got really into it and she still plays it today and going into our later childhood, me going to University, even now, like the best 1 on 1 time that I have with Beth is playing Wii sports together.

I'll say I like this, I can never criticise my mum and dad for anything because like it's the toughest thing that they have got to go through, you know the sacrifices and things like that. The thing that, the only thing that frustrates me a little bit and maybe I should bring it up with my mum and dad a little bit more because Beth will happily stay quiet if she does not have to speak and we are always wanting her to speak and if I, if I like facetime them now and something like that and I start talking to Beth, I try to ask her a question and she'll be really quiet and my mum and dad will fill in for her and they'll speak over her and that bugs me a bit because I feel like it's not helping her with her speech but it's also not helping mine and her connection which is maybe why I talk about the Nintendo Wii so much because that's me and her in a different room, the doors closed. It's an opportunity for me and her to actually spend time together where there's not really that many other opportunities to do that so yeah and she's, oh man, she's amazing at it as well. She has this technique with the controller right where she, she has such grace she kind of gets her hand down and flicks it up to the side, the same hand motion and she'll be like stern her face will have no expression and she'll flick it up to the side and the ball does the most, the maddest like swerve so she can set up her shot beforehand she goes right to the edge of the lane as far as you can go and she does this swerve and honestly 9 times out of

10 it's a strike, like every time. I remember having, we are at my Auntie's house having christmas dinner and they had like, the dining room has a mirror looking into the conservatory and Beth has taken herself off to play a bit of bowling, the adults and some of the kids are chatting, and I could see her through the window, I was having a little look like 'nice strike' and then we keep chatting and then I have another look and she has got like 8 strikes in a row like that and she's just slinging them out but yeah so that is a big part of our enjoyment together and the sort of stuff that we did.

Discussion

Toby's portrait touches on a number of aspects of his sibling relationship, with the central theme being the role played by the Nintendo Wii games console growing up. The portrait will be unpacked with regard to the narrative focus points outlined by Rodríguez-Dorans (2022), these being characters, orientation in time, complicating action, result and evaluation, small stories, special narrative features, and the abstract. Whilst these provide a framework for analysis, specific attention will be given to the more affirmative nature of the portrait throughout the analysis in order to ensure the research aims are met.

Characters

In creating the narrative portrait, it was important to ensure that the characters central to Toby's narrative were represented in a manner that reflected their importance to his story. Recognising the limitations of a portrait's size alongside the focus of the research project, the result was a portrait that centred around family. The first character to mention is Toby as the narrator, throughout he references his feelings about certain events firmly placing himself within the narrative he is telling. Alongside Toby as the narrator, his sister Beth is the central character of the portrait. The stories focus on Toby's relationship with Beth and how this has shifted over time, with the role of playing video games together being a consistent thread in the story. Wider family also feature in the portrait. For example, Josh, their brother, is mentioned at the start as the reason the family got their Nintendo Wii. Toby's parents are then brought into the story initially to get the Nintendo Wii and getting 'really into it' alongside the children. As the portrait progresses, we see Toby discussing his relationship with Beth, and the role his parents play in that over time. The final section sees Toby recount a funny story of a family Christmas in which a number of characters are referenced, both explicitly (their Aunt) and implicitly as being at this Christmas dinner.

Orientation in time

The orientation in time of a narrative refers to a number of things alongside temporality. With regard to this portrait, significance is also found in the geography of the story and the everyday as a setting. Beginning with the context of the portrait, this is found at the beginning with Toby reflecting on getting a Nintendo Wii on the release date, which places Toby's childhood, and the beginning of the

portrait in the mid-2000s. This is not the only timeframe in which the extract takes place, the present day becomes the focus as we move into the discussion around calling his family from abroad. This aspect also places the portrait geographically, with Toby juxtaposing the time spent together at home as children with his present day awareness of the importance of putting work into his relationship with his sister and his parents' role in this. This is with regard to Toby now living abroad and not seeing his family as much, a context that is implied in his reflections. Whilst this can be seen in the central geographical orientation of the portrait, we also see more at-home reflections on space, for example, Toby's feelings about being in a different room and this privacy affording a certain kind of catch-up with his sister that he is very fond of.

Alongside the temporal and spatial orientations of Toby's narrative, we also see the portrait play out firmly in the everyday. The stories and reflections are ones about Toby's everyday life and more, arguably, mundane experiences. This, of course, relates to the focus of the research project, with this being an aim that is considered whilst bringing the portrait together. Furthermore, considering the affirmative potential of narrative portraits this setting recognises the more joyful and humorous aspects of Toby's narrative as part of his everyday family life. Toby's account makes clear the everyday joy of living alongside his sibling. Davies (2023) refers to 'living alongside' as a key element to what makes siblinghood unique arguing 'the idea that, even if sometimes too close for comfort, the heightened proximities of sharing a home with one's sibling(s) afford a particular kind of 'living alongside' is important' (ibid: 96). Davies' reflection acknowledges the ups and downs of siblinghood in the everyday, with the 'heightened proximity' bringing with it potential for frustrations alongside closeness. From Toby's portrait, we see how this living alongside can be characterised by fun through things such as playing together. This playing together is something that characterises Toby's relationship with Beth, and more widely his family's relationships with their brother and parents being involved. The centrality of everyday joy to this portrait is important when considered within the context of joy deficit within disability studies (Sunderland et al., 2009; Shuster and Westbrook, 2022) as it can be seen to actively reject deficit understandings of living with a sibling with learning disabilities.

Complicating action

For Patterson (2013), complicating action coding works to 'relate the events of the story and typically follow a 'then, and then' structure which gives a linear representation of time and permits an open-ended series of events to be related' (ibid: 31). Within the portrait, we see a number of these moments. Starting with the family acquiring their Nintendo Wii which becomes the central focus of the portrait. The joy and fun that characterised Toby's narrative are captured in these moments, with the portrait using the game console as the foundation by which this aspect of the narrative is made clear. The Nintendo Wii is central in all reflections in the portrait, even as we move into the next complicating action of Toby moving away and keeping in contact with his family. We see this time spent playing the Nintendo Wii as almost his 'gold standard' of hanging out with his sister which he uses as a comparison point for more difficult interactions such as facetime with his family. This context makes clear why playing the Nintendo Wii with his sister is

important to Toby as it helps to facilitate this 1 on 1 time. This time is essential in Toby's view to keep his connection to Beth, especially now he does not live at home. Considering the relational nature of siblinghood (Davies, 2023) this activity is presented as a core way Toby and Beth enact their sibling relationship. The fact Toby puts in such effort to keep this connection and is frustrated when he feels his parents unintentionally block this, once again pushes back against a deficit understanding of siblinghood and learning disability. Whilst in one sense this is a very everyday portrait of sibling gaming and hanging out, it takes on a new meaning when considered alongside commonplace narratives of deficit (Meltzer and Kramer, 2016). Viewed alongside the notion of a 'joy deficit' Toby's portrait offers a story of inclusion, love, and fun that pushes an affirmative narrative.

Result and evaluation

The result and evaluation sections of the narrative link closely to the complicating action. For Riessman (1993) evaluation is 'the soul of the narrative' (ibid: 21). Patterson (2013) equally captures the importance of this aspect arguing it 'mediates the crucial 'point' of the story, thereby justifying its telling, and it reveals the narrator's perspective on the events being told' (ibid: 31). In Toby's portrait, we can trace the result and evaluation alongside the complicating actions. Starting with acquiring the Nintendo Wii games console, we see the result being this special time that Toby and his family spend playing together and the closeness this brings, even now in the present day. Toby's evaluation of this is one of closeness and appreciation for this time together alongside admiration for his sister's talent at the game. The joy that runs through the portrait is drawn from this fun that characterised their childhoods, and the present as shown when Toby sees his family in person. The reflection that it is 'the best 1 on 1 time that I have with Beth' makes clear the importance Toby places on this time.

The result and evaluation that come with Toby's reflection on moving away is found in his feelings about calling home and speaking to Beth and his parents. The result of the action of moving away is calling home and not getting the chance to speak directly to Beth, or feeling as though this is not the quality time that he was having at home with her. In the evaluation of this Toby is both considerate of his parents' experience whilst also making clear his own frustrations around the situation. Toby's reflection on his parents touches on feelings of sacrifice and an understanding from Toby of the challenges people with learning disabilities and their families face in the UK (Goodley et al., 2014; Ryan, 2019). It is interesting how Toby does not feel as though he can really criticise his parents for this reason even though his frustrations lie with their role in his relationship with his sister. This feeling reflects wider research around siblings of people with learning disabilities and structural factors that influence their childhoods. Toby's notion of sacrifice is rooted in the structural ableism that families of people with learning disabilities have to navigate throughout their lives (Goodley, 2014). Furthermore, whilst the want for his sister to talk more in the calls is partly reinforcing developmental narratives that are important to call out (Gabriel, 2021), there is also an element of care to this standpoint, both for his sister but also in the understanding he shows for his parents.

Small stories

Small stories refer to the sections of the narrative where the participant recounts a story from beginning to end that could be read on its own, for [Rodríguez-Dorans \(2022\)](#) the key to a small story is the plot, and the 'potential to be analysed as units of meaning' (ibid: 31). Whilst not all portraits will have a small story embedded due to the size limitations of most research outputs, Toby's portrait includes the story of the family Christmas dinner. This story has a distinct beginning and end, with the story starting with the discussion of Beth's bowling technique and finishing with the reflection 'so that is a big part of our enjoyment together and the sort of stuff that we did'. The story can be analysed for its content as an individual story, but also as part of the wider narrative. The story is funny, with Toby juxtaposing the nature of Wii bowling with his sister's approach to playing to create a funny image of focus. This evokes a sense of banter between the siblings, something that was apparent more widely in his narrative. Furthermore, where this could be read as Toby making fun of his sister, this humorous framing is combined with genuine admiration for how good Beth is at the game. These factors come together to give an insight into Toby's sibling relationship that is built on humour and care echoing [Lampert and Ervin-Tripp's \(2006\)](#) reflection on teasing as requiring closeness and understanding.

Special narrative features

Special narrative features refer to the themes of the narrative and give an overview of what could be potentially important to focus on in a narrative portrait. Toby's portrait is centred around the core themes of his narrative: humour, closeness, and joy. By focusing on gaming with his sister, these themes are each afforded space within the portrait whilst also having a narrative thread that ties the extract together. Furthermore, the central aim of a narrative portrait of speaking to the research focus ([Rodríguez-Dorans, 2022](#)) is met with the portrait giving an insight into affirmative reflections on siblinghood and learning disability. The portrait makes clear Toby's sense of humour. This is seen at the beginning with the reflection on how the family came to get their Nintendo Wii with Toby poking fun at his brother for how obsessed with it he was. For [Lampert and Ervin-Tripp \(2006\)](#), teasing is considered a sign of closeness as it requires an understanding from both parties so as to not be interpreted as an insult. Furthermore, [Davie's \(2023\)](#) reflections on 'living alongside' refer to a heightened proximity which brings with it space for closeness but also at points more conflictual teasing. Whilst Toby's narrative portrait features humour and teasing that is quite 'light' this approach to sibling teasing offers an opportunity to analyse joking in a manner that is understanding. The humour of Toby's portrait is linked clearly to the affirmative nature of the piece, with his approach to storytelling contributing to a portrait that is, in most places, fun and centred around the joy of their childhoods.

Closeness is the second theme that came through in Toby's narrative and is apparent within the portrait also. The overall piece points to the family being close, with a specific focus on Toby's relationship with Beth. The most obvious reference to this is in the section around moving away and maintaining closeness, with Toby reflecting on the shared experience of playing video games as a central part of their sibling relationship. Whilst the discussion is centred around the

challenges of maintaining a relationship whilst living away from home, we also get a sense of how important fun is to Toby and Beth, as shown in the reflection 'it's also not helping mine and her connection which is maybe why I talk about the Nintendo Wii so much because that's me and her in a different room'. Here, Toby makes clear why he spoke about gaming so much in his narrative as it brings with it one-to-one time to spend with his sister that they both really value. His want to 'help' their connection is driven by his awareness that it is harder to have this 1-on-1 time when he is not at home and therefore he feels some concern about how they will maintain their closeness.

The final special narrative feature from the narrative that was incorporated into the portrait is joy with Toby's portrait being one that highlights the fun of their childhood and even in the present day how having fun is one of the central ways he and Beth maintain their relationship. The portrait is framed around fun and the joy that comes with that, with Toby's narrative presenting an understanding of siblinghood and learning disability that places joy at its centre. Toby was keen in his narrative to ensure he captured the fun that he feels is a core part of his sibling relationship as further highlighted by the section within the timeline dedicated to the Nintendo Wii. All of the special narrative features come together to give an insight into the everyday of Toby's childhood, and the fun of playing games with his family. In this regard, the portrait works to counter deficit understandings of siblinghood and learning disability. Taking into account the joy deficit that can be argued to exist within disability studies ([Sunderland et al., 2009](#)), Toby's narrative, and the portrait created from it, ensure joy is presented as a prerequisite for understanding Beth and his relationship.

The abstract

The abstract attempts to capture the overall point of the narrative, answering the question: what is it telling us? This information is then used in bringing together the portrait, giving a basis to guide the researcher around what is important to include. Toby's narrative captures the nuance of everyday siblinghood ([Davies, 2023](#)), whilst centring joy and humour in particular. In bringing together the portrait, the recurring references to the Nintendo Wii felt like the perfect place to focus the piece as it allowed both reflections on fun and joy but also gave space for Toby's reflections on closeness and having moved away. Narrative portraiture offers an insight that allows for the nuance of everyday sibling relationships to come through. Toby's feelings are contextualised amongst his wider narrative to ensure that his words are given appropriate space for the reader to understand his experiences. For example, the reflections around his parents and calling home are tied up in wider feelings about keeping a connection to his sister. Similarly, the joking about his sister's bowling skills is read alongside the admiration and joy he feels when gaming with her. These factors come together to give an overview of Toby's narrative that centres joy, closeness, and humour in an affirmative way.

Conclusion

Narrative portraits offer one avenue through which to address the joy deficit in disability and siblinghood research. By giving insight into

participants' narratives, in their own words, the nuances of living with siblings are captured in a way that does not inadvertently contribute to commonplace narratives of deficit. Reflecting on their research with parents of disabled children, Thomas (2024) argues 'parents revolt against dominant conceptions of parenting a disabled child as a source of despair, fear, and no future' (ibid: 2). The same can be said from a sibling perspective for Toby, with his narrative portrait actively rejecting a deficit understanding of his sibling relationship in favour of one that places joy and fun as key parts of the relationship. Goodley (2023) calls for the centring of the human in understandings of learning disability, something that we can see in Toby's narrative portrait. Toby's portrait presents his experience as a sibling in a nuanced light, where challenges can be acknowledged but in a manner that avoids playing into commonplace deficit narratives of disability and siblinghood. For Chapman (2005) portraiture 'depicts the multiple layers of contexts represented by events and people' (ibid: 28), this understanding makes clear how the context a portrait affords lends itself to nuanced presentations of lived experience. Furthermore, throughout the portrait we see the care the siblings feel for each other, captured in Toby's concerns around maintaining the relationship after moving away. This nuance is achieved through the space extended to Toby's narrative that allows for an overview that can highlight different aspects of his experience in his own words. For Smyth and McNerney (2013), this is a political choice, with there being a sense of accessibility to the method in how it allows a clear picture of the participants' experience to be presented to the reader. They build on this, arguing 'as researchers we have a moral and ethical responsibility beyond the 'thin' imposed views of university ethics committees—to work with and advance the lives of those who are institutionally and systematically the most excluded and silenced' (ibid: 17). Acknowledging this, it is important to note the need for more research that explores the experiences of people with learning disabilities as siblings, an argument that has been made by Richardson and Jordan (2017). Whilst Toby's portrait can be seen to contribute to narrative repair regarding understandings of siblinghood and learning disability through the affirmative narrative it offers, it is not the complete picture, and therefore more research that centres people with learning disabilities' sibling experience is needed.

Data availability statement

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

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Ethics statement

The studies involving humans were approved by The University of Sheffield research ethics committee. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study. Written informed consent was obtained from the individual(s) for the publication of any potentially identifiable images or data included in this article.

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Who decides on time? Mad Time as a disruptor of normative research politics and practices

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There is an increasing recognition of the epistemic injustice perpetrated against individuals deemed mad, leading to a push for the inclusion of their voices in research and academia. Nevertheless, despite being predominantly enacted as progressive, the inclusion of individuals deemed mad within research practices and spaces often fails to disrupt the ways in which methodology is conceptualized and practiced, contributing to the ongoing psychiatrization and exclusion of Mad practices and, more broadly, failing to produce alternatives to carceral responses to madness. In this article, I consider both the potential for methodology to produce temporal violence as well as the potential of Mad Time to disrupt normative and often sanist research practices. To achieve this, I weave together theorizing on Mad Time, post-qualitative inquiry, the experiences of peer support workers, and my own temporal conflicts in attempting to madden research within academia. I propose three ways in which Mad Time may provoke alternative methodological practices that move us closer to epistemic justice: rethinking the concept of data, embracing stumbling, circling, scrambling (becoming), and valuing variations in pace. I conclude by reflecting on the possible implications that thinking with Mad Time might hold for both research and activism, both within and outside of academia.

KEYWORDS

Mad Time, madness, PQI, psychiatrization, methodology

Introduction

“Sometimes you just want your curtains closed [in a hospital room]...I’m having this sort of memory of the darker days, of both internally, but also wanting a darker room for whatever reason, and then when people come in and just thrust open your blinds and just completely walk into your space because its whatever time on their shift and decide for you that its morning.” (Paula)

For individuals deemed mad, time is often thrust upon us. For example, in inpatient units, others decide what time of day it is and what we should be doing according to that time. Days are scheduled around others’ timeframes and according to normative expectations of what should happen and when. We are diagnosed according to time; we might fail to get out of bed at the right time, and our minds and bodies move too quickly, slowly, or inconsistently. Time can often feel as if it is standing still: we wait for the doctor, for medication, to be listened to. We wait to be allowed to resume life: our future on hold. At other times, time is rushed by: meetings with the psychiatrist, diagnosis, and discharge happen before we have had time to grasp what such occurrences mean. Our own paces, orientations, and conceptualizations of time are dismissed or devalued.

Such temporal violence, produced through entanglements of psychiatric logic and mental health systems, is similarly produced through methodology. Temporal research orientations and practices often go unremarked, yet shape how, when and where knowledge is produced. They shape the questions researchers ask and how they are answered. They include ideas about where research starts and stops (and thus what constitutes research), how research should progress, and expectations concerning the pace of research. Such temporalities play a large part in the ongoing dominance of psychiatric thinking and the ongoing exclusion and erasure of Mad knowledge and practices within academia and beyond (Russo, 2022). The temporal orientations of academic knowledge production have long excluded those deemed Mad. As Sheppard (2020, p. 39) describes regarding the exclusion of disabled bodyminds more generally, we are “too slow, too fast, too uncontrolled, too reliant, too different, too much and also not enough.” In this article, I use Mad Time to consider the temporal aspects of research that uphold psychiatrization through the exclusion of Mad knowledge and practices.

Furthermore, I consider Mad Time as a potential disruptor to normative research temporalities, inviting us to “imagine and enact methodology otherwise” (Eales and Peers, 2021, p. 164). Rather than conceptualiz madness through pathology and fear, I consider how we might value the ways in which bodyminds¹ slow down, speed up, ruminate on the past or future, and refuse to do things at the supposedly appropriate time. How might we recognize the important learnings that can come from Mad “moments of rupture and disorientation?” (Davies, 2024, n.p.). How might Mad Time stimulate new ways of enacting methodology that move us toward alternatives to psychiatrization and the abolition of carceral systems and responses to distress?

Whilst entanglements of time, ableism, heteronormativity, and methodology have been explored from crip and queer perspectives (Atkinson et al., 2024; Humphrey et al., 2023; Humphrey and Coleman-Fountain, 2023; Rodgers et al., 2022), explorations focused more specifically on sanist research temporalities and the potentials of Mad Time are limited. Such explorations are important and pressing, given the increased inclusion of lived experience within mental health research, often in ways that continue to psychiatrize and fail to recognize the generative potential of Mad knowledge and practices (Rose and Kalathil, 2019; Landry, 2017; Ross et al., 2023; Russo, 2022; Sinclair et al., 2023a). This epistemic injustice has far-reaching consequences, contributing to ongoing carceral responses to psychiatrized distress.

I start by outlining Mad Time as described in the existing literature, albeit with broad strokes, while acknowledging that explorations of Mad Time, like madness, “should always leave room for different views and stories” (Smith, 2024, np). I then describe the relations that have provoked my thinking about Mad Time, research politics and practices. Such relations, loosely but not wholly contained within a research project examining the politics of inclusion, include temporal conflicts I experienced attempting to madden research and navigate academia as a Mad scholar, theorizing on Mad Time, practices of post-qualitative inquiry, past experiences of peer support

workers and their visceral reverberations into the present, and dreaming of Mad futurities.² Using quotes from peer support workers as provocation points, I provide three examples of how methodology can be exclusionary and reinforce psy-knowledge, as well as the ways in which Mad Time may disrupt such practices. I consider the ways in which, as researchers (whether as researchers employed within academia, individuals contributing to research, or those of us doing our own theorizing and activism outside of academia), we may draw on Mad Time to unsettle sanist research practices and deepen our activism.

Mad Time

In thinking with Mad Time, I am stirred by Cosantino’s (2022, p. 1) powerful poetic meditation on Mad trans time, describing Mad trans time as “a deeply embodied theorizing, challenging and actively disrupting normative temporalities, blurring the artificial boundaries between past, present, and future; knowing and (un)knowing; being and becoming.” Mad Time signifies multiple and diverse ways of thinking, feeling, and doing time that coincide with experiences of madness, the “material differences of life as part of a subaltern group” (Price, 2024), and that sit in tension with sanist conceptualizations of the ‘right’ way of being in/through time. Bruce (2017, p. 1) provides examples of Mad Time: “the quick, restless time of mania; the slow, sorrowful time of depression; the infinite, exigent now of schizophrenia; and the spiralling, zigzagging now-then-now-then of melancholia.” McEwan (2023, p. 35) works toward an obsessive-compulsive Mad Time, describing how such experiences “both speed up time in the frantic repetition of obsession and compulsion” and yet externally “appear slow and illogical.”

Mad Time, like queer and crip time, may involve a refusal to embrace curative futures, time outside of productivity, flexible time, and departures from linear progress, particularly linear narratives of recovery (Kafer, 2013, p. 34; Sheppard, 2020). Mad Time “tears calendars, smashes clocks, ignores calls for timeliness, builds makeshift time machines, writes “poetry from the future” (Bruce, 2021, p. 204). Drawing from their lived experience, Morrigan (2017, p. 56) proposes that “queer temporalities” of “traumatized minds” provide “a creative, flexible and nonlinear way of relating to time,” opening up possibilities for different ways of being in the world, rather than a “problem, a tragedy, or an unfortunate condition requiring a cure.” Thus, Mad Time defies “the Eurocentric, heteronormative, capitalist, rationalist clock-time that reigns in the modern West” (Bruce, 2021, p. 204). It defies normative futures associated with rationalist subjects. It defies, as Paula describes in the opening quote of this article, having to ‘rise and shine’ at a certain time as defined by clinicians within a mental health unit. We madden time whenever we “infuse the disruptive potential of [madness] into normative spaces and interactions” (Price, 2015, p. 269).

¹ I use the term ‘bodymind’ to disrupt colonial and psychiatric enactments of mind–body as separate (see Clare, 2017; Price, 2015).

² By Mad futurities, I refer to Fritsch’s (2016: 11)’s work, imagining the “flourishing of critical practices of an elsewhere and elsewhere of disability,” whereby madness is valued in the present, rather than overcome or cured in the future.

Thinking with Mad Time involves centring the temporal expectations and activism of individuals who encounter psychiatric classification and violence. As an aspect of Mad theorizing, Mad Time both critiques and aims to transcend sanism whilst recognizing the intersection of sanism with other forms of oppression (Costa and Ross, 2022; LeFrançois et al., 2016). It invites consideration of the potential of madness to subvert the status quo, disrupting dominant conceptualizations of madness as only ever requiring cure, treatment, or management.

Numerous studies have not been written specifically about Mad Time but have, and continue to be, influential in thinking about Mad Time and knowledge production, and therefore require honoring here. First, the concept of Mad Time is heavily indebted to scholars and activists theorizing on crip, queer, and trans time (Bruce, 2017; Davies, 2024; Kafer, 2013; Price, 2024; Samuels, 2017). These concepts have, in common, a critique of normative assumptions about time and their oppressive effects, a centring of the experiences of individuals and communities that fail to measure up to such 'normal' temporalities, as well as provoking alternative ways of being in the world that not only accommodate but value difference. Such experiences are often intimately intertwined, with many theories interweaving them within their analysis. Bruce (2021), for example, writes of both Black and Mad Time, whilst Cosantino (2022) and Morrigan (2017) speak of Mad, trans, and queer time. Kafer (2013) weaves together feminist theorizing with queer and crip time, including both disabled bodies and minds under the banner of crip time.

Whilst recognizing the intimate entanglement of Mad Time with other temporalities, I join others in arguing that Mad Time holds generative potential as a distinct analytical concept (Smith, 2017). In particular, I position Mad Time as overlapping with, but separate from, crip time. Mad Time, as an aspect of Mad studies, communities, and activism, has developed alongside but distinct from crip and disability communities. For example, Mad studies, a discipline that brings together Mad research, theorizing, activism, and Mad culture, has a complex relationship with disability studies (Jones and Kelly, 2015). Whilst emerging partially via critical disability studies, Mad activism and scholarship has tended to occur separately from disability politics given the ambivalence around mainstream disability studies ability to theorize madness, and more critical perspectives within disability scholarship "pushed to the margins" in favor of more pragmatic (and fund-able) research (Cohen, 2017, p. 2; Sapey et al., 2015). Mad Time, as a distinct analytical concept, centers the temporal experiences and activism of individuals who encounter psychiatric classification and violence and draws specific attention and critique to "psy-centred ways of thinking, behaving, relating, and being" in a way that cannot be done via a more generalized crip lens that focuses on ableism (Menzies et al., 2013, p. 13). Similarly, Mad Time may be useful, but cannot speak fully, to the distinct experiences and ways of theorizing and responding within crip and disability communities.

Whilst I argue for the utility of these as distinct concepts, I also recognize the intimate entanglement between not only crip and Mad experiences but also a range of other experiences and that "we-who are not one and the same – are in this troubled world...together" (Braidotti, 2022, p. 241). There remain many similarities not only between experiences but also in the way such experiences are responded to as only ever requiring cure, treatment, or management. As such, there is great benefit in drawing from these concepts when

theorizing ways in which normative temporalities may be disrupted within academia and beyond. I continually learn from crip theorizing and crip communities, and I desire to recognize the value of thinking together without "flatten[ing] the diversity of disabled/mad/chronically ill/debilitated communities" (Gauthier-Mamaril, 2024, p. 1). Within this article, I thus quote those who have written on crip time where such theorizing overlaps, or may speak to, Mad experiences, thinking, or practices.

Furthermore, it is imperative that thinking with Mad Time involves a consideration of First Nation knowledge and practices of resistance to the ongoing violence of both colonial and sanist temporalities. First Nation peoples from colonially named 'Australia' have orientations to time that differ from colonial time and temporalities (Yunkaporta, 2023). Indigenous scholars (activists, poets, artists, teachers, and elders) have highlighted how such orientations enable meaningful engagement and sustainable relationships, disrupting colonial academic temporalities (Wright et al., 2016). Writing as a wadjela (white person/colonial settler) on the stolen lands of the Wadjuck Noongar people, I reference such knowledge tentatively, given that they are not culturally bound to me, and the risk of appropriation within academia is significant. Indigenous worldviews and practices are often sidelined through academic claims of new ontologies and practices, despite Indigenous theorizing having always acknowledged complex and ever-shifting entanglements of the social and material (Arnold et al., 2021; Milroy, 2021; Price, 2024; Todd, 2016).

Mad Time as an analytical concept is also indebted to activists and scholars who have theorized and practiced alternative ways of thinking and doing within Mad communities (Beresford and Russo, 2021; LeFrançois et al., 2013; Russo and Sweeney, 2016).³ My own thinking about Mad Time would not be possible without peers: individuals with lived experience of psy-oppression and/or misfitting with normative temporalities who have shared their experiences and theorized alongside me, both within the scope of a formal research project (which I discuss shortly) as well as more broadly within the community. Whilst many did not use the language of Mad Time, their sharing of experiences becoming entangled with, and resisting, normative temporalities and understandings of such have provoked my own theorizing and maddening of time. Mad individuals, particularly those outside academia, are rarely considered theoretical provocateurs and critical theorists. Nevertheless, those who draw on madness in their thinking and doing always have subversive potential.

Lastly, in considering the generative potential of Mad Time, I resist romanticizing madness or Mad Time. As highlighted by Bruce (2021), madness, both one's internal experiences as well as the experiences of being medicalized and discriminated against, can be both a source of pain and a resource for revolution. Samuels (2017) makes the same argument about crip time, describing how, in their life, it has operated as a form of liberation as well as a site of loss and alienation. There are "risks that haunt these temporalities. Manic time might rush recklessly into danger; depressive time might become so

³ I list only a few references here, in addition to those I quote throughout this article, in the hope they provide a gateway to further exploration and reading. It is vital that we recognise that Mad theorising and activism happens within, as well as outside of, academia.

deeply wedged in woe that it does not ever get free; schizophrenic time might be crushed between history's hurt and the future's threat; melancholic time might collapse under the weight of the lost and dead that it carries" (Bruce, 2021, p. 229). Considering Mad Time means acknowledging its potential for both pain and revolution.

Methodology/anti-methodology

My thinking for this article is contained somewhat within the scope of a formal research project exploring the politics of inclusion for peer support within mental health systems, which I describe here. However, as I argue in this article, Mad Time encourages consideration of how the boundaries we draw around a research project are artificial, with researcher desires, experiences and histories, technology, material environments, discourses and so on, seeping in and out of the research assemblage, affecting and being affected by the knowledge produced. By assemblage, I refer to relations of socio-material elements (bodies, meanings, emotions, objects, places, and technologies) organized and held together temporarily that produce knowledge: subjects, objects, and concepts in particular ways. The notion of a research assemblage reflects the complex and ever-shifting entanglements (co-researchers, contributors, consent forms, technology, methods, ethics committees, time, desires, and theories, among others) that produce knowledge (Bettez, 2015; Ellingson and Sotirin, 2020).

Time was not the focus of this research project. Instead, the project sought to explore the effects of peer support becoming increasingly entangled with mental health systems, defined and operationalized as a formal occupation. The research involved several practices of inquiry: thinking with Mad and post-humanist theory, discussions with peer support workers, analysis of policy documents and research practices (Bacchi and Goodwin, 2016), collaborative and solo practices of coding with wonder (Mac Lure, 2013), mapping (Martin and Kamberelis, 2013), and experimenting with afflexivity (Setchell et al., 2021). I conceptualize these as inquiry practices, as I did not follow rigid protocols nor systematically apply a technique or procedure to produce knowledge, as implied by the concepts of 'method' and 'methodology' (Koro-Ljungberg, 2016). Rather, I sought to think with Mad and post-humanist theories and concepts alongside others with experience navigating mental health systems. The research aimed to not represent inclusion but rather deconstruct it, to agitate and provoke alternative ways of thinking about inclusion, peer support, and madness in ways that may ultimately change how madness is responded to.

Unlike conventional methodology, Mad thinking and doing is far from systematic or replicable. Whilst methodology seeks to structure, fix and contain, madness invites us to be unruly, to disrupt, to refuse, and to dream otherwise (Bruce, 2021; LeFrancois and Voronka, 2022; Smith, 2024). Madness as methodology involves refusing to be loyal to systemic or fixed research methods at the expense of generating alternative knowledge and practices. It means adopting an anti-methodological stance, challenging conventional boundaries of method and turning instead toward the "unmanageable, incredible, illegitimate" (Smith, 2017, p. 1). However, all research studies, particularly that situated within academia, follow some

sort of established path. Our work is captured by dominant forces, even if it does veer off in all sorts of illegitimate and wonderful directions that disrupt the status quo at various points. Thus, I describe partly methodology and partly madness as "anti-methodology" (Smith, 2017, p. 1).

A total of 15 individuals who had experience providing peer support within mental health systems in a formal capacity contributed to the research via one-on-one discussions. Such discussions might be referred to in more conventional qualitative research as dialogic interviews. However, as I will go on to discuss shortly, I resist such language that suggests a researcher gathers 'data' from/on contributors. Rather, my desire, influenced by the values of both peer support (Stratford et al., 2019) and survivor research (Faulkner, 2004; Landry, 2017), was for us to share our experiences and practices as peer support workers within the (Australian) mental health system, "actively engaged in the creation of knowledge" together (Motta, 2016, p. 42). Given the nature of peer support roles as involving the drawing on one's own lived experiences of distress and/or navigating psy-systems, our conversations often traversed our experiences as both 'service user' and 'worker' within mental health systems. I do not conceptualize the experiences shared in these discussions as 'representative' of peer support worker experiences but rather as providing provocations to think and feel "otherwise" (Taguchi, 2012, p. 272). Our conversations were held in person, over the phone or online, lasting 1–2 h.

After these conversations, I initially mapped the relations in which peer support work becomes entangled, plugging in policy and research analysis, Mad and post-humanist theorizing, with that shared in our discussions. Contributors were then invited to come together to continue this mapping of the affective relations that peer support workers become entangled with through inclusion (see Sinclair et al., 2023b; Sinclair and Mahboub, 2024 for further detail). Four individuals who had contributed via the initial one-on-one discussions joined this workshop, alongside myself and an additional lived experience academic. Together, we used prompts to map potential relations that produce dominant ways of thinking and responding to distress and those that provoke alternative possibilities.

Whilst time was not the focus of the research, it was an affective element that continually surfaced throughout our discussions and became an important part of my thinking about the effects of inclusion (see Sinclair, in press). As I thought with/through such temporal aspects, I also increasingly reflected on my own journeying through academia, both as a Mad scholar misfitting academic temporalities (Price, 2024; Rodgers et al., 2022) and my attempts at research aligned with Mad anti/methodologies and survivor research within sanist academic entanglements (Faulkner, 2004; Landry, 2017; LeFrancois and Voronka, 2022; Smith, 2024). From the beginning of my research journey, normative temporalities had clashed with my desires to value survivor research, Mad ontologies, and my own Mad ways of thinking, feeling, and existing. For example, I struggled to formulate a fixed and linear methodological plan for ethics approval without having spoken to contributors about the different ways they may desire to undertake the research and knowing this may change over time as we create knowledge together (see Sinclair and Ridley, 2022). However, without the language or framings to conceptualize such, these tensions largely went unspoken, pushed within as something potentially wrong with me. As Davies (2024; n.p.) highlights that individuals deemed mad, such as myself, are taught to "distrust their/our own gut reactions,

feelings, sensations, and emotions, and to even deem our feelings untrue, unrealistic, or false through mental health interventions.”

It was not until such affects became entangled with thinking alongside fellow peer workers and others who have theorized on temporalities that I started to make sense of such tensions. Moments where peer support workers spoke of time intensified my thinking, making me pause, whilst at the same time, connections were fired up as we recalled and shared incidents, details, and feelings. I also noticed temporal tensions between what was left unsaid and what was assumed within incidents or practices. Temporalities as a concept became an important part of my thinking about the effects of peer support inclusion (Sinclair, *in press*). However, more relevant to this article, this thinking and feeling extended to my reflections on methodology and the research journey itself. I became increasingly aware of the deep entanglement of normative temporalities within research politics and processes and how these sat with/against my own research practices.

Ironically, during this process, my bodymind slowed. I struggled to get out of bed. Tasks took me what seemed like so long, and my brain would not work as quickly as I wanted it to. Everyday conversations and decisions were hard as I struggled to process the information coming in and integrate it with what was already known. I have been to this place many times before. I know with time, it will pass. I work with people close to me to clear the decks – I cancel appointments and work, and we sit tight. We eat frozen meals. I potter around. Spend time in the garden. Go for slow walks. Slowly. Slowly, the world starts to feel safe enough to re-enter, my bodymind feels strong enough to re-engage, and I return to operating at a pace considered normal within academic spaces underpinned by neoliberal, capitalist, colonial, and patriarchal ideals. Doing so requires leaning on my socio-economic privilege, performing as a ‘supercrip’ to catch up on what is considered my reduced productivity (Clare, 2015).

It is easy in such moments for me to curse my bodymind for failing to keep up with normative temporal orientations and for failing to do research in a way that aligns with academic schedules and expectations (Price, 2024; Rodgers et al., 2022). However, readings on Mad, crip, trans, queer, and Indigenous time alongside the knowledge and experiences of peer support workers have enabled a growing part of me to celebrate my bodymind’s resistance to the normalized ideals of productivity within research assemblages and the chrono-normative ordering of research. Rather than seeing bodyminds as needing discipline, I started to use Mad Time to consider such failures as productive, becoming curious about how such thinking might be applied to methodology. How might my own, and others’ Mad experiences of temporal misfitting be considered valuable?

My own experiences form part of what is contained within this article. I share my reflections on both engaging in this research and navigating different temporal orientations and expectations alongside the experiences of others as part of my commitment to becoming mad in our thinking and doing together. Bringing forward and sharing one’s experiences of madness and using such experiences to inform relationships, research, and activism is an integral part of peer work, survivor research, and Mad theorizing. However, drawing on a relational ontology, I am uncomfortable positioning the work as autoethnographic. I do not see myself and my experiences as a separate piece of ‘data’ to be analyzed alongside those of others, nor do I position them representative of a wider cultural experience. Instead,

I conceptualize my body, history, emotions, desires, and experiences as deeply entangled with the research, both shaping and being shaped by it. For example, I consider the experiences and knowledge shared within discussions with peer support workers as produced *in relation* to other elements, including bodily responses, ideas, objects (technology, consent forms), expectations (for example, what we thought the other might want to hear), desires (for example, what I/they/we wanted to get off one’s chest), and dominant discourses (shaping what can and cannot be made sense of and articulated).⁴ I thus share my own experiences and reflections, not as representative, but as provocation points to think differently about madness and methodology.

A further element, post-qualitative inquiry (PQI), is also interwoven in this research. Similar to Mad methodologies, PQI rejects pre-existing methods and definitions of how research should be done, arguing that these methods and research protocols serve as exclusionary measures and, too often, simplify complex and multifaceted phenomena. Instead of prioritizing methods, PQI requires a commitment to thinking rigorously with theory and concepts (Koro-Ljungberg, 2016; Lather and Pierre, 2013; Liddiard et al., 2019; Murris, 2020; Pierre, 2021). Taken together, both Mad methodologies and PQI refuse “to make mad subjects both knowable and governable, or to make sense of that which cannot and should not be reduced to the rationalist’s desire for uniformity, consistency, universality and conformity to the dominant logics of the sanestream” (LeFrancois and Voronka, 2022, p. 108). Woven together, these approaches push toward enacting research as performative rather than representative, political rather than ‘objective’, prompting questions such as ‘What do our research practices produce?’ and ‘In what ways might we identify and support relations that produce alternatives to psychiatrization?’

These relations between Mad Time, PQI, peer support workers’ experiences, my own Mad desires, academic processes, and expectations cannot be separated into a set of linear and replicable methodological steps. Rather, they are part of the research assemblage: deeply entangled and collectively, they have produced what the thinking outlined below. I desire this study to be taken as a provocation, to open up ways for thinking about madness and methodologies as diverse and multiple, rather than taking such work as representative of Mad experiences and relations to time or arguing for the ‘right’ way to do research. I have used a variety of inputs to think through and against my own experiences of madness and temporality, including supervision, engaging with affective tensions and differences within transcripts, and thinking with theory across disciplines. However, I will have undoubtedly erased experiences and thinking that do not reflect my own. Madness exists in many forms, with many varied implications. Furthermore, my privilege and positionality in the world have, in many ways, sheltered me from the more oppressive intersections and effects of misfitting with normative temporalities. The thinking I share here is thus messy and unfinished, and I offer it up imperfectly in the hope it may grow and become otherwise.

⁴ See for example, Youngblood Jackson and Mazzei (2011) conceptualisation of the interview as an ‘already failed practice’.

Mad time as a potential disruptor

I turn now to provide three examples of how Mad Time might be productive in disrupting normative and sanist research practices: rethinking data, embracing stumbling, circling, scrambling (becoming), and valuing stopping, starting, slowing down, and speeding up. I begin each example with a provocation from discussions with peer support workers where we talked about entanglements of time, mental health systems and/or experiences of distress or madness. I use these as a springboard to consider temporal violence and how such effects are potentially replicated or unsettled within methodological practice, offering my own experiences as a point of reflection or difference.

Rethinking data

“The clinicians are only seeing people at that stage. There’s a whole life out there, there’s a whole other story, and a whole other dimension to what’s going on for that person” (Rebecca)

In our discussion, Rebecca and I talked about how clinicians often take a snapshot of one’s life, slicing and cutting time, assuming this is representative of one’s life. Mental health interventions are also often framed around the cutting of time: before diagnosis and treatment and after, when one is deemed recovered and, therefore, deemed suitable to return to societal roles. Time outside of intervention is rarely imagined or comprehended (Clare, 2017; Kafer, 2013).

This concept of temporal cutting can similarly be considered within the conceptualization and use of ‘data’. Data collection and analysis are commonly enacted as a linear, temporally bound process, where what counts as data is defined around a cutting of time. This occurs before ethics is approved, research proposals are written, and data is collected. Events or affective forces before (and sometimes even during) are unspoken of, hidden from view. Similarly, data is collected and *then* analyzed. Such a framing assumes a start-middle-end of research and knowledge that is discovered, captured, and isolated within such processes. Researchers are expected to think only about the data and nothing outside of the data.

Within such framings, the researcher is enacted as detached, following a strict methodological process to extract “truth nuggets from subjects,” uncontaminated by any influences that come before or during such data collection (Ellingson and Sotirin, 2020, p. 3). Individuals with experience navigating madness are predominantly produced as objects to either study or gain information from. Analysis happens after, belonging to the academic.

Within my own research, what might be referred to conventionally as the data set includes discussions with peer support workers, Australian mental health policy, and academic literature concerning peer support work in mental health systems. Following traditional conceptualizations of data, it is assumed that the knowledge produced is my own to claim, garnered from a rigorous independent analysis of temporally bound data.

Mad Time, however, invites us to blur such boundaries. Mad Time is messy and disruptive, blurring past, present, and future, subverting neat temporal boundaries around data. Morrigan (2017, p. 50) describes how, as someone living with complex trauma, they do not

experience time as a “straightforward, orderly procession from the past, through the present, to the future.” Rather:

“the past rushes up on me with the urgency of the present. The future creeps out of crevices, leaking into the now. The future and past are intimately entwined, the present produced in their merging. Sections of time are uprooted and relocated” (Morrigan, 2017: 50).

Mad Time prompts a reconsideration of normative conceptualizations of data and, subsequently, who owns the knowledge produced. It invites us to speak to and incorporate, within research, the messy, overlapping nature of time and what occurs before, after and throughout data collection and analysis. To speak to, as Rebecca describes, the “whole other story” that’s going on outside of what’s traditionally considered data: the complex socio-material entanglements that produce knowledge. Thinking with Mad Time highlights that what we write about as research outcomes is not just from data as predominantly conceptualized. Rather, as researchers, we think from/through multiple experiences (both our own and others), concepts, subjective theories, desires, and material entanglements, folding across past–present–future, and it is these relations that produce knowledge.

For example, I research and write as a queer feminist, as having cared for disabled bodyminds, as a mother and community member, as having a lifetime of moving through (and not moving through) the world as someone who experiences periodic, debilitating distress, and as a facilitator of peer work training and supervision. I had been thinking and feeling through the implications of peer support inclusion within mental health systems for many years, with/in the community, before the formal structure of the research project. I have spoken with and listened to hundreds of individuals with experience of peer support, both before and during this research. My thinking and feeling about temporalities, madness and peer support happened whilst teaching; through attempting to crip time as part of my teaching practice alongside other instructors and theorizing with fellow peer workers during training sessions. It involved teaching my child, born during this research, about access needs and the importance of waiting so that we may all “move together” (Fritsch et al., 2021). It involved having my own expectations and understandings of time challenged by and through parenting, terminal illness, grief,⁵ madness and a pandemic. It happened with and through books, blogs, First Nation poetry, conversations at conferences, and social media posts. All of these are brought into and inform the research and yet extend beyond so-called data. The knowing and affect generated are thus collective, created through “relating criply and madly” (Eales and Peers, 2021, p. 164). It is these deeply entangled relations that produce knowledge.

In this way, thinking with Mad Time resonates with post-qualitative and Indigenous scholarship that argues for a consideration

⁵ Kenny et al. (2019) speak to some of the ways in which lived experiences of bereavement challenge normative linear understandings of bereavement and ‘recovery.’

of data as embodied, relational and dynamic, assembled through the intra-action of individuals that contribute to the research, material objects, emotions, bodies, and cultural discourses within particular times and spaces (Ellingson and Sotirin, 2020; Koro-Ljungberg et al., 2017). It provokes a consideration of the deeply relational aspects of knowledge production and the potential of Mad individuals as critical theorists and activists. Whilst decentring the researcher as a sole agent, it invites us to consider our responsibility for our contributions, including how we are situated within relations that produce psy-logic and practices (Russo, 2022). It invites us to consider the way we make temporal cuts when conducting and describing methodology and what this means for the knowledge produced. As St Pierre (2014) prompts, what inquiry practices and concepts get left out? It asks us to consider whether data can ever be representative or whether it leaves out a “whole other dimension” (Rebecca). Bringing Mad Time into conversation with methodology thus has the potential to support further thinking, creatively and messily, about how we might conceptualize and use data differently in ways that do not simply replicate dominant ways of responding to madness.

Embracing stumbling, circling, scrambling (becoming)

“That was the circuitous path to becoming a peer worker” (Ben)

In our discussion about peer support, Ben shared what he described as his “circuitous path” to becoming a peer support worker, one that resembled many of the journeys shared with me, my own included. Our paths to becoming peer workers felt convoluted, folding back and forth, and full of intervals. Such journeys are circuitous in comparison to the expectation that one progresses through normative life stages in a straight line – from past to present to a (curative) future (Kafer, 2013; Sheppard, 2020). Such expectations are particularly present for peer support workers, who are expected to recover and stay recovered (Sinclair, in press). Yet, such temporal framings do not reflect my own experiences, nor many of the other peer support workers I spoke with. My early employment history, for example, is littered with jobs abandoned due to an inability to maintain a consistent temporality of ‘climbing’ a career ladder, to drop down, return, start again, and move sideways.

Applying such “circuitous” orientations to research provokes a consideration of how traditional research practices are not only temporally bound but also chrono-normatively ordered. That is, methodological processes predominantly assume a linear, logical order from point A to point B, whereby the stages along the way are separable and distinct: from literature review to research question to data collection, analysis, and representation. This cleanness, linearity, predictability and consistency are considered the hallmarks of quality qualitative research (Koro-Ljungberg, 2016). Mad Time provokes a rethinking of such ordering. Rather than pathologize stumbling, circling and scrambling, Mad Time invites us to consider its potential value.

Looking at Koro-Ljungberg’s (2016) diagram of linearity in qualitative research processes, for example, I attempted to map my own methodological process between the discrete categories outlined in traditional methodological processes. My map looked like a higgledy-piggledy of back and forth, with so much folding between

categories that the categories no longer made sense. What would traditionally be understood as data collection, for example, happened simultaneously as analysis. Different analytical questions emerged from plugging together various theories, feelings, experiences, methods, and thinking. As I thought and felt with others, the original research questions no longer fit, prompting me to circle back and reconsider the aims and tools needed (see Sinclair and Mahboub, 2024). So often, academic processes and expectations push us to continue moving forward, remaining fixed in our methodological orientations, only looking back as a reflection, not an intervention. And yet, had I stuck with the previous research questions and methods, I would have potentially replicated existing knowledge, refusing to listen to what was emerging from thinking and feeling collectively with/in the community.

Mad Time invites us to let go of what we thought the research would look like and what we thought it would become to allow for something new to emerge. Mad Time wrenches us out of what is expected. It allows for shifting ground for the unknown, giving us permission to take new paths to circle back when needed. We might understand that methods, affects, theories and analysis are not clearly defined by time but rather deeply entangled. We might think about the ways in which data may shape the researcher’s research question, prompt a new literature review, challenge, or create a new theory. Valuing these circuitous processes potentially enables something new to emerge within research that is less likely to replicate paths of psychiatry and other dominant frameworks of thinking and responding.

Valuing variations in pace: stopping, starting, speeding up and slowing down

“Everybody else is going on with their lives, and poor pathetic Chloe has to go and have a little hospital stay” (Chloe)

As a final example, Mad Time provokes us to consider how we might shift research practices to not only accommodate but rather deeply value variations of pace. As Chloe articulates in the quote above, it is so often assumed that when we are experiencing madness, we must stop, exclude ourselves from life, and “disinvite myself from citizenship for a period of time,” as another peer support worker, Alex, described. Similarly, we are excluded from research because we fail to fit organizational time (Atkinson et al., 2024): schedules, priorities, pacing, and deadlines. However, sometimes, this is when our work may be the richest.

Doing research as someone who has a relationship with various forms of madness, the timing of my research practices is rarely smooth and consistent. My madness predominantly involves slowing down or stopping whilst the world seemingly races by without me. Moments, days, and weeks stretch out in a never-ending hopelessness. During these times, it would outwardly appear that my thinking and doing comes to a halt. Bruce (2021) describes such depressive time as lagging, dragging, lingering, and acting in slow motion, the value of which is unrecognizable to capitalist productivity. Sometimes time seems to stop whilst my mind goes around and around like a carousel with no way of me hopping off. Often, I will struggle to think in the morning, yet my mind will race at night. At other times, my madness fractures linear time: present

and future disappear down a rabbit hole of past regrets, or I have a sense of impending doom that situates me squarely in the future, mostly paralyzing me but sometimes speeding me up in a flurry of nervous activity. In some of these moments, I can speed through and write large chunks of text, embracing a Mad Time that entails racing thoughts, restlessness, and hyperactivity.

Whilst usually only the latter speed is appreciated within academic research, when my bodymind slows, I can sink into research and experience a depth of thinking with theory. I do 'analysis', as suggested by St Pierre (2014) whilst living: whilst weeding the garden, showering, walking, and resting. Doing so enables a depth and breadth of thinking that is otherwise discouraged within an academic assemblage that values productivity and publications. Slowing down, for example, enables me to notice the knots in my stomach and the sense of unease produced through "hot spots" in the transcripts (Mac Lure, 2013, p. 172). Davies (2024) describes these as "maddening moments." Instead of viewing these moments through a frame of pathology, we might wonder what these moments offer for research. I notice unease spread its tendrils into my everyday life, where I often see dominant beliefs and practices enacted throughout workplaces and personal relationships: psy-discourses, peer job description forms, mental health policy, peer support workers, and peer education. Embracing my own slowed temporality fosters a connection to the research. With the flexibility of choosing one's own hours, working from home, using the Internet, and receiving support from family and friends, I have produced some of my best work during this 'depressive time'. Rather than grinding toward a point of exhaustion for both our bodies and the planet, Price (2024, p. 78) highlights that "slowing down creates pauses and interstices that enable political theorizing, organizing, and intervention."

Of course, there have been times where I have simply not been able to work because my bodymind has refused to move at all, insisting that I stop and rest. There are times when research may be enriched by stopping if needed or desired. There may also be times when we recognize the need or desire to move quickly when certain bodyminds desire or allow. We might consider the felt urgency of need: the way in which Mad thinkers are often told to slow down and be patient, that change takes time, whilst our peers continue to be harmed and neglected. Thinking with Mad Time is not about valuing a certain pace or temporality over another, but rather is about making space for multiplicity, honoring the productive nature of multiple speeds, temporal orientations, and desires within our research practices. It pushes us to consider how research practices might enable people to contribute at their own pace, knowing that doing so will enable not only epistemic justice but also deeper, richer research and activism.

One of the ways I did this in my own research was to provide materials in various formats ahead of time, allowing people to reflect/think/feel when and how it suited them. I invited individuals to contribute via various formats and did not restrict this to scheduled meetings, underpinned by a desire to unsettle the temporal disciplining regime of appointment time (Soldatic, 2013). How often within mental health assemblages must individuals be ready to recover when their appointment time with the worker is scheduled? Too often, one's bodymind must adapt to the temporal rhythms of neoliberal systems. I tried to madden time by flexing to meet the needs of those I was meeting-morning, evening, breaks, talking slow, talking fast, and rescheduling. Other ways in which research might center Mad Time

is through embracing asynchronicity and hybrid technologies, dedicating additional time to collective work, and enabling people to immerse themselves in flexible ways over the course of the research, as is often proposed for crip bodyminds (Atkinson et al., 2024).

Piepzna-Samarasinha (2022), for example, describes how embracing crip time means letting go of "abled panic" when technology fails, when certain deadlines are missed, or when someone's access needs change. Rather than "giving up because the process is inefficient, non-standard, or slow," we think outside the box, draw on other resources, and get creative (Gauthier-Mamaril, 2024, p. 1). As Gauthier-Mamaril (2024, p. 1) describes, "we all become risk assessors and masters of project management for our own energy and pain tolerance reserves." Mad Time, like crip time, is generative. Mad individuals often have fabulously creative strategies for navigating the uncertainty of Mad Time. For myself, I have learnt to prioritize certain tasks that require speed or quick thinking when it best suits my bodymind, knowing other times might be suited to deep reflection. I am learning to let go of able-bodied panic, valuing instead the varied speeds at which my own and others' bodyminds work. In working with contributors and fellow researchers, Atkinson et al. (2024) described crippling time as "prioritizing flexibility around hospital appointments, taking time off sick, waiting for antibiotics and other medications to kick in, and managing sudden hospitalizations....we build in contingencies, use organizational technologies to share and document our work so someone else can jump in when needed." We may consider how such alternatives also madden time.

Whilst I provide these examples, we must also recognize that as part of academia or services reliant on funding, our ability to work collaboratively, to produce knowledge collaboratively, and to think about how to do so is constrained by temporal norms. For example, Scholz et al. (2019) document how temporal resources available within academia constrain research that positions individuals with experience navigating distress and/or mental health services as equal partners in the conceptualization, design, and undertaking of research. Collaborative research requires relationship building, developing collective viewpoints, being able to think together, reading with and against theory and struggling collectively, and the resources to do so are often limited on the ground. Furthermore, the time required for individuals deemed Mad to contribute to research, including the time of emotional labor and theorizing, is rarely recognized or valued (Faulkner and Thompson, 2021; Papoulias and Callard, 2022; Ross et al., 2023). I continue to sit with my own ethical discomfort in failing to unsettle many of these sanist effects within my own processes of inquiry whilst recognizing that the work of maddening methodology and the academy is collective.

Conclusion

I started this article with two provocations. First, conventional methodologies are often temporally violent, producing effects similar to those of psychiatric relations. Second, Mad Time may be generative in subverting methodology in ways that move us toward the abolition of carceral understandings and responses to madness and a future in which madness does not equate to mandatory cure or treatment. Thinking and feeling with Mad Time and methodology holds the

potential for moving beyond simply including individuals deemed mad into normative research approaches, where madness is accommodated or tolerated. It encourages us to consider not just more time in research but rather challenges the underpinning normative and normalizing expectations of pace, scheduling, and linear logic embedded in sanist methodological concepts and practices. As a starting point, I have proposed just a few ways Mad Time may be generative: by prompting a rethinking of data, embracing stumbling, circling, scrambling (becoming), and valuing variations in pace. By leaning into Mad Time, we might reimagine what counts as research and how research is conducted in ways that produce richer, more epistemically just knowledge and in ways that have practical implications for changing the world in which we live.

Thinking with Mad Time has implications not only for academia but also for other sites where knowledge is produced: in classrooms, during peer support catch-ups, within advocacy groups, around the vending machine, or on the communal couch in inpatient units. In what ways are we already maddening time in these spaces? How might recognizing and valuing Mad Time change the way in which we gather as activists or practice activism? How might the concept of Mad Time enable us to respond differently to our own and others' madness in our everyday practices? Whilst I have argued that Mad Time is generative in its potential to disrupt normative research politics and practices, I look forward to further exploration of its generative potential both within and outside of academia and other conventional research spaces.

Data availability statement

The datasets presented in this article are not readily available because of ethics requirements. Requests to access the datasets should be directed to aimee.sinclair@postgrad.curtin.edu.au.

Ethics statement

The studies involving humans were approved by Curtin University Ethics Committee. The studies were conducted in accordance with the local legislation and institutional requirements.

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"[T]he most precise and thorough understanding of the situation we are struggling to change": re-capturing emancipatory disability research

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This article seeks to contribute to a refoundation of the analytic, qualitative and quantitative methods associated with Emancipatory Disability Research (EDR)—an episto-political approach to disability research which places lay disabled people in positions of authority over research design, operation, and analysis of projects undertaken by professional academics. The argument of this article is that a significant reason for EDR's meager impact on political practice, the burnout and disillusionment of some of its most talented proponents, and its failure to develop beyond limited applications in sociology and disability studies lies in the disjointed and asymmetrical development of its aims and methods. I indicate, particularly, that the core evaluation signifiers for EDR's success (that disabled people concretely benefit from the research, and control both its future direction and the uses made of it) rested on an initial demand from disabled activists for scientific rigor and a realist ontology in research which were subsequently rejected by EDR's academic advocates. Without a grounding in the scientific method, a meta-theory of subject-object relations and knowledge, or an evaluative framework for the objective accuracy of input concepts; EDR's research framework prevented practitioners from producing outputs for which there was a demonstrable demand, while promising forms of research for which there was not.

KEYWORDS

emancipatory disability research, disability activism, scientific method, research democratization, credible commitment problem

1 Introduction

This article seeks to contribute to a refoundation of the analytic, qualitative and quantitative methods associated with Emancipatory Disability Research (EDR)—an episto-political approach to disability research which places lay disabled people in positions of authority over research design, operation, and analysis of projects undertaken by professional academics. The argument of this article is that a significant reason for EDR's meager impact on political practice, the burnout and disillusionment of some of its most talented proponents, and its failure to develop beyond limited applications in sociology and disability studies lies in the disjointed and asymmetrical development of its aims and methods. I indicate, particularly, that the core evaluation signifiers for EDR's success (that disabled people concretely benefit from the research, and control both its future direction and the uses made of it) rested on an initial demand from disabled activists for scientific rigor and a realist ontology in research which were subsequently rejected

by EDR's academic advocates. Without a grounding in the scientific method, a meta-theory of subject-object relations and knowledge, or an evaluative framework for the objective accuracy of input concepts; EDR's research framework prevented practitioners from producing outputs for which there was a demonstrable demand, while promising forms of research for which there was not.

EDR was proposed in the early 1990s by (mostly) disabled academics in Britain and the Irish Republic who were involved in or sympathetic to Disabled People's Movements (DPMs) in those countries¹. Almost universally coming to disability politics after beginning their research careers in sociology and social policy, EDR's progenitors came to see the prevalent research practice of their fields as a constituent parts of a disabling society, rather than motors of social change. So long as research was controlled and disseminated by unaccountable academics, these thinkers argued, it was bound to reproduce the social prejudices and material inequality of the institutions which birthed it—including their exclusionary and condescending attitudes to marginalized groups, and assumptions that social or welfare policy is the preserve of elites.²

Their response was to invert the social relationship underpinning academic research. EDR proposed a rigorous set of research principles to address the inconsistent preferences of researchers and disabled participants' previously limited influence over their behavior. At its core, it made disabled people's co-operation with research conditional on researchers abiding by six epistemological, ontological, and methodological principles:

1. The use of the "social model of disability" (i.e., the claim that disability is socially, rather than biologically caused) as the theoretical basis for research.
2. Surrendering claims to objectivity in favor of participants and movement actors emancipatory political commitments
3. The focusing of research topics and project design around outcomes which will bring either practical material benefit to disabled people, or empower them to remove disabling barriers
4. The devolution of power over research planning and decision-making to disabled people to ensure maximal accountability of researchers to their subjects and/or the DPM.
5. A commitment to describe participants' personal experience of disablement without distortion, while representing it as part of a collective experience of oppression.
6. The selection of research methods to reflect the preferences and priorities of participants and the DPM (Stone and Priestley, 1996, p.706).

1 For the purposes of this article, I use 'DPM' to refer to the aggregation of self-organised networks or groups of disabled people involved in political work (broadly understood to include protest action, politically informed models of self-empowerment and service provision, etc). I bracket here, for the sake of simplicity, the question of whether ideological, social or organisational distinctions between such networks signify multiple distinct movements, or a single movement with multiple tendencies. 'The DPM', in singular, will accordingly be used throughout the rest of this piece.

2 For early statements of this critique see, *inter alia*, Morris, 1989 (esp. pp. 5–7); 1992; Oliver, 1992; Zarb, 1992; Barnes, 1992; Abberley, 1993.

Of these principles, decentralization of power over how research is planned, conducted and evaluated is the most central—it is the accountability arising from this which safeguards the appropriateness of methods, theoretical groundings, research topics, representation of participants and empowering outcomes implied by the other five. It is grounded in a recognition that researchers do not come to disabled people as autonomous moral and ethical agents; but as conditioned by and dependent on structures which are divorced from disabled people's interests, priorities, and welfare. Academics are compelled to write papers acceptable in style and content to their colleagues—not disabled people more generally—to be successful in their field; and to make recommendations that are (plausibly) amenable to governments, firms, and state agencies—not necessarily disabled people—to influence social policy.

Given these conflicting incentive structures "disabled people and their organizations should be wary of researchers," and attempt to make them equally dependent on disabled participants or movement agents (Barnes, 1996a, p. 107). Operationally, devolution should, wherever possible, take the form of a supervisory group of disabled participants and/or movement representatives empowered by the research agreement to make binding decisions about the research's aims, structure, and activities at each stage of its design, implementation, and dissemination. If researchers fail to follow its instructions, the exit of the supervisory group would effectively negate consent agreements with all participants. Where this is not possible, any participant's consent should, minimally, be made conditional on their approval of finished reports or papers (Barnes, 1992, p. 122–3).

This article argues that the failure of emancipatory research to generalize was primarily the result of a problem in its negotiating framework – not the moral or epistemological foibles of its academic proponents, the hostility of its opponents, or its funding environment (as other scholars have argued). The second of its six principles obliges all interested parties to sacrifice claims to objectivity, while the fifth focuses researchers' attention on the subjective experience of disablement as their primary data point. Given that potential participants already know very well what *their* subjective experience is, and DPM actors are likely to recognize it from their political and community building work, EDR's attractions to them are modest. Emancipatory research solves the problem of researchers' commitment, but at the expense of committing everyone involved to findings which add little to disabled partners' projects of self-empowerment or social transformation. The incentives of non-academics to give their time and effort to it, then, are minimal.

This hypothesis is not so much new as it is previously underdeveloped. Finkelstein (1998, p. 860) pointed out forcefully in a short book review that a focus on the personal experience of oppression "uncover[s] little more than the known debilitating effects of living in a world designed for people with abilities." Without turning their attention to the objective dynamics and structures of the social world which cause disabled people's disadvantage, emancipatory researchers make a fetish of participants' control of research practice while ignoring that they already know (and thus already control) the knowledge under discussion. Similarly, during Mike Oliver's (1997, p. 84–5)

disengagement from emancipatory research, he recognized that he and his colleagues had made a category mistake in their treatment of objectivity by equating it with scholarly detachment from, and neutrality on, contentious political questions. While the latter was impossible to reconcile with commitment to emancipatory struggle, research could begin from the assumption that social phenomena have objective effects, while still committing to produce results which inform liberatory political strategies. No sooner was this point made, however, than Oliver dropped it—failing to draw out its implications for an alternative research practice.

I build on these insights by investigating what we might call the demand-side of EDR to evaluate how well it addresses problems in the research process for the disabled participants and activist groups it aims to recruit. I firstly recast EDR as a solution to a Credible Commitment Problem (CCP)—a control mechanism by which disabled stakeholders prevent researchers' deviating from the terms of their initial agreements with participants. When so viewed, previous accounts of EDR's failure to generalize across disability research, resting on the moral and professional preferences of those involved, are problematized. Inconsistent preferences can only be addressed by forcing parties to negotiate over which will be fulfilled and how in their collaborations. Stating that researchers hold preferences conflicting with EDR and act on these by spurning or sabotaging it is, therefore, a description of its limited growth, not an explanation for it.

In place of these, I argue that EDR failed to grow because it did not address a consistent preference of lay disabled people for actionable research outputs; based on assessments of objective processes in the social world instead of experiential responses to them, and using the scientific method to give confidence that emancipatory strategies could be built around their conclusions. I do not argue that this preference is universal. Clearly, some disabled people (not least the academics discussed in this article) do distrust the concept of objectivity, and value experiential research above all other kinds. I do argue, however, that a contrary preference is substantially and continuously expressed by activists and those sympathetic to their movement—limiting their incentives to enter negotiations over how research is conducted.

I evidence this, first, through the demand for scientific approaches to research proposed in the first critiques of research practice advanced within the Disabled People's Movement (Hunt, 2022a,1972,b). In these, I argue, the scientific method and a commitment to ontological realism are presented as integral to any meaningful negotiation over research practice: safeguarding research outcomes which lay participants can use in their other projects, and preventing both parties behaving inconsistently in the face of contradictory incentive structures. In the following section, I argue that this view is reflected in disabled participant and activist behavior during the period of EDR's emergence and propagation. Those projects conducted with EDR advocates which both participants and movement bodies recognized as successful forewent, in large part, EDR's emphasis on representing subjective experience. Similarly, the evidence we have of participant evaluation of projects which followed EDR's second and fifth principles more closely are largely ambivalent.

The literature on which this article is based comes, predominantly, from between the early-1970s and mid-2000s. This is, in large part, a reflection of the paucity of EDR studies produced in the last 20 years (as discussed in Section 3). While contemporary examples of EDR exist, and are discussed in Sections 2 and 5; these are a small minority within both the overall EDR literature and contemporary disability research.³ As I seek to explain EDR's failure to generalize since its most productive period in the 1990s, this piece treats recent studies as tokens of their broader framework, rather than situating them in contemporary debates around co-research and expertise-by-experience⁴. This is, of course, something of a stylisation, but one (I hope) which allows us to draw insights on the strengths and weaknesses of EDR as a research project.

2 Disability research as credible commitment problem

Qualitative research requires the active consent of its subjects. Unless willing to limit their data to material already in the public sphere, or picked up through *ad hoc* observations, researchers must convince other human beings to answer questions, be observed, engage in odd experiments or research settings, etc. Participants might humor the researcher for any number of reasons—from an unselfish respect for science, to a (usually modest) payment for their inconvenience—but induced they must be. Clear information on the hows, whys, and whats of the research project are essential for establishing a moral economy⁵ in which consent can be given and maintained. A blossoming ethics and scientific integrity industry (including departments and committees at universities, academic publishers, and scientific associations) monitors the fairness of the resulting contracts between researchers and researched, and exacts costs on errant researchers. The odd scandal aside, the system works relatively well most of the time.

Inducements to participate in research are more problematic for members of marginalized and oppressed groups; particularly disabled people. Even bracketing the historical exploitation of, and violence toward, disabled subjects in the course of (social)

3 In contemporary disability research in the Global South, "emancipatory disability research" is often used to describe a much looser framework than the one I interrogate here. This approach prioritizes participants' skill development over their control of research practice—by, for example, using research projects to build networks between participants from different communities (Cutajar and Adjoe, 2016, p. 506), or training local disabled people to conduct research under academic supervision (Deepak, 2015, pp. 6–7).

4 For an overview of such debates, see Dembele et al., 2024.

5 I, following Thompson (1971), use "moral economy" to refer to both relatively stable mores or customs which align the behavior of one party with the expectations of another, and shared moral commitments which allow the recognition an activity's aims and value to converge across social positions. In the case of research, the latter might include: the enlargement of knowledge; the practical solution of some (social/medical/practical) problem; or the obligations of all parties to abide by the terms of a Participant Agreement. For an exegesis of Thompson's concept, see Edelman (2012, pp. 55–58).

scientific research⁶, many grounds which motivate others to engage in research may be irrelevant for disabled people, and the trust which mediates other research relationships may be lacking. The enlargement of science, or solution to general social problems, are likely less motivating for those whose marginality hinders them benefitting materially from either, and even cash payments can become the unwanted focus of scrutiny by benefits agencies to those trapped in long term unemployment (Rickard and Purtell, 2011, pp. 37–38). The benefits for researchers are clear—published qualitative research is a prerequisite for career advancement for many social scientists—but often indistinct (or simply more trouble than they're worth) for disabled subjects. This asymmetry gives the impression of exploitation, wherein the disabled researched give their time and effort for outcomes which will only payoff for the researcher. As one rehabilitation specialist has pointed out, the obvious question for participants remains: “what’s in it for me?” (Amsters, 2019, p. 66).

This, combined with the proactive equation of marginality and vulnerability by university and funding bodies’ ethics committees, incentivizes the researcher to offer a more comprehensive, and often more stringent, research contract to potential participants. It is likely that ethical problems and procedures—particularly those concerning participants’ consent—will be defined in greater detail, with more responsibilities falling to the researcher to cultivate trust rather than simply avoid unethical activities. The proposed research outcomes are likely to be mooted as directly relevant to policy or cultural issues which disabled people are perceived by the researcher as having a stake in. Researchers might, further, promise to use conceptual frameworks sympathetic to the (real or perceived) interests and self-conceptions of disabled people; thereby turning research outputs into an authentic representation of participants’ views, concerns, and experience.

While in many individual cases researchers succeed in offering a set of rules, topics, and analytic framework acceptable to enough people to make a given project viable, there are serious plausibility issues with each element of the expanded offer when stated abstractly. Thomas (2024) has recently noted the significant practical difficulties in enacting comprehensive research agreements in a reflection on a project he conducted with people with learning difficulties. The result of expanding the set of rules that a researcher must abide by is often a written research agreement so long and convoluted that it’s unlikely that any participant (let alone one denied proper access to mainstream education) could fully familiarize themselves with it—leaving the researcher and their professional colleagues the arbiters of compliance (pp. 11–12). If the agreement commits the researcher to activities which are particularly time intensive—such as allowing all participants to review analytic methods before results are written up—these may conflict with funders’ strict timetables and are vulnerable to being ignored as the project progresses. This is particularly so when waiting for access adaptations to allow participants to complete these tasks stretches research timelines

even further (pp. 19–20). Similarly, no matter how detailed the initial agreement, the researcher will still be faced with unexpected questions of power and consent during research practice. In disability research, these often arise from the actions of service providers whose presence is essential for the project to take place, but who may influence participants in ways which frustrate initial visions of consent and trust (pp. 15–17).

Even if these problems could be ameliorated, there are significant political contradictions in the research relationship which cannot easily be resolved. I, through Hunt (2022a, 1972, b), will argue below that there is not just a power asymmetry between researcher and researched, but a structural opposition on who should receive the social and political authority associated with expertise. Disability is recognized by governments and civil society as an area requiring policy intervention, and those recognized as expert on it form a candidate pool for insider advisory positions (renumerated or otherwise) for the bodies which make and enact these interventions. Researchers are incentivized to keep this candidate pool small and credentialed to minimize competition, and to use research to prove their own suitability for it. Disabled people, on the other hand, are likely to want it radically widened to give them direct influence over decisions which affect their lives.

The research relationship, then, bears all the hallmarks of what economists and political scientists call a credible commitment problem (CCP) (North and Weingast, 1989, pp. 806–808). One party (in our case the researcher) is incentivized by the need to secure agreement to some action to make extensive commitments in the short-term which they either cannot, or will be incentivized not to, honor in the long-term. The leverage of other parties to control this behavior is time-limited, and will largely disappear once initial agreement is given. In our research context, once participants’ data is collected, their leverage is largely spent; and ethics bodies are often incapable of solving disputes due to uncertainty over how complaints should be made and adjudicated (Underhill, 2014, pp. 72–75).

Participants will, therefore, likely find themselves unable to enforce the terms of initial research agreements unless action is taken at the outset to limit which incentives the researcher can follow. As the problem emerges from inconsistencies between the researcher’s preferences at different points in time, this must increase the dependency of researchers on participants (or at least a subset of them) throughout the research process: typically through constructing repeat interactions, formal arrangements which decentralize power away from the researcher, and mechanisms for monitoring compliance with research agreements which are independent of the researcher and their institution (Morriss and Ku, 2022, n.p.).

3 Emancipatory research and the CCP

As a solution to the CCP, emancipatory research should have performed well. It forces repeated interactions between researchers and disabled subjects (or those sharing their concerns), such that the researcher must consider the implications of their actions at later points in the project. It creates mutual dependencies between the researcher (who requires active consent for each project stage)

⁶ For the alternative view, that contemporary disability research cannot be separated from the most abusive historical forms of research practice (particularly those undertaken in the Third Reich), see Sierck and Radtke, 1984; Pfeiffer, 1994; Mostert, 2002.

and their subjects (for whom participation in project design creates greater interest in successful completion). That the DPM organized tens-of-thousands of disabled people at the time emancipatory research was proposed (Barnes, 1996b, p. xi) should have provided researchers with an extensive recruitment pool, and the DPM with the capacity to make use of research outcomes through political action. Theoretically speaking, EDR principles 1, 3, 4, and 6 put all the incentives in place for academics, disabled participants, and DPM actors to negotiate fruitfully over the form, content, and outputs of research practice.

Despite this, EDR failed to make much impact on disability research beyond its original progenitors; some of whom became disillusioned with it in the two decades following its initial flourish. Rix et al.'s (2020, pp. 1035–1037) study of participatory research with sensory and intellectually impaired people between 1996 and 2016 found only a small minority of projects which involved subject- or movement participation of long enough duration and high enough devolution to plausibly count as “emancipatory” (and even here this label was not necessarily appealed to). Their work further indicates that this is not because the CCP had been solved by other means. The comparatively small number of English, Spanish or German language studies discovered by them which involve disabled participants at all implies that incentivizing recruitment remains a significant general problem for disability researchers.

EDR's failure to generalize across disability research, despite solving a central problem of recruitment and consent, requires explanation. Those offered hitherto by both its proponents and detractors remain, however, unconvincing. Critics in the 2000s pointed to negative reactions to EDR within and without the academy, but without proving the relevance of these to its growth potential. Worth (2008, p. 311) suggested that academics might feel “intimidated” by the rigors of EDR's principles and prefer to avoid it. Certainly, both disabled and non-disabled academics experienced its initial proposal in this way: “a thinly veiled threat” to jeopardize non-compliant researchers (Bury, 1996, p. 113), or to impose stringent rules on those academics most likely to be disabled people, potentially curtailing their research careers (Shakespeare, 1996, p. 117). When emancipatory research is viewed as a response to the CCP, however, this appears as a feature, not a bug. Any solution to inconsistent commitments involves limiting researchers' ability to follow all their preferences through the application of leverage by other parties. This necessarily includes the threat of non-compliance or interference (i.e., by encouraging others not to participate in, fund, or disseminate particular projects). If participants and movement actors correctly judge their leverage, however, researchers should be compelled to enter negotiations despite their feelings of intimidation.

Similarly, Danieli and Woodhams's (2005, pp. 290–291) argument that EDR's growth was limited by the alienation of potential participants who aren't aligned with the DPM's theoretical and political commitments is something of a non-sequitur. There were, and are, plenty of disabled people who disagree more or less strongly with the DPM, but to prove that this impacted EDR's growth relative to other forms of disability research it must be shown that either:

- a) this translates into a preference not to engage in emancipatory research compared to traditional, researcher-led projects;
- b) the absence of participants who feel alienated could not be compensated by the pool of potential participants opened by movement actors' involvement in recruitment.

Danieli and Woodham offer evidence for neither claim.

EDR proponents, conversely, focussed their (often emotive) self-criticism on its inability to meet its 4th principle of material benefit for disabled participants and empowerment opportunities for the movement—at least, relative to emancipatory researchers themselves. For Mike Oliver (1998, pp. 12–4), this resulted from researchers like him's failure to think beyond the researcher/researched distinction; leaving a hierarchical division of labor, and an unequal distribution of the benefits of research, unquestioned. This rationale is somewhat question-begging. If, as Oliver (1997, p. 188) holds, academics' ideological or “unconscious” biases toward this hierarchy are strong enough to jeopardize emancipatory aims; it must be explained why the participants and DPM actors the paradigm forced them to negotiate with were systematically unable to neutralize these subjective drives. Behavior based on ideological and epistemological commitments, or even the effects of the Id, are no less valid objects of negotiation for EDR than those arising from rational calculation. To say they caused research projects to diverge from their aims describes a process of failure (accurately or otherwise), without giving cogent reasons as to why divergence occurred.

More pragmatically, Gerry Zarb (1997, p. 50) pointed to the contradictory interests of funders and emancipatory movements to explain the impossibility of desired research outcomes. The DPM was antagonistic toward the state, the charity sector, and the medical establishment; yet these funded most disability research and would be unlikely to finance projects designed to undermine them. The funding reality at the time was more ambiguous than Zarb's neat explanation suggests. The entrance of charities and NGOs into research commissioning incubated, in many instances, a *laissez-faire* approach to project design (Mercer, 2004, p. 126). While plenty of funders rejected all radical projects, enough were prepared not to interfere in researcher-researched agreements for non-emancipatory researchers to plausibly fear (at least for a while) that EDR might become hegemonic (Bury, 1996, pp. 113–114; Danieli and Woodhams, 2005, pp. 291–292).

What these accounts lack is a reckoning with *whether* the potential participants and movement actors EDR was being offered to felt much need for it. It is assumed by all the accounts above that, if EDR could attract appropriate funding and stick steadfastly to its six core principles, it would unproblematically be perceived as a good, at least by those disabled people sympathetic to the DPM. In the next two sections, I outline significant evidence to the contrary. Disabled activists were very keen on controlling research practice; but far from enthusiastic about the commitments to reconstructing subjective experience and symbolic orders entailed by EDR's 2nd and 5th principles. Sympathetic non-activists, from the limited accounts we have of their evaluations, appear to value opportunities to share their unmediated experience with others, but to attach little value to the analytic and dissemination procedures EDR associated with this activity. Instead, we see

(most clearly amongst activists and more ambiguously amongst other participants) a continuous preference for research into the economic, political, and social determinants of disablement, using the scientific method, which could inform disabled people's engagements with those phenomena.

4 Paul hunt: objectivity and the scientific method in early critiques of disability research

One of the earliest English-language critiques of academic-led disability research is Paul Hunt's sustained response to Miller and Gwynne's (1972) book on residential homes in Britain. Miller and Gwynne were invited by residents (including Hunt) at one such home in Surrey to investigate disputes between them, management, and staff over how much control residents should have over the rules and operational decisions of the home. Miller and Gwynne's conclusions had little bearing on the meat of these disputes. Instead, they argued that residential homes were the inevitable product of the economic parasitism and emotional dysfunction of disabled people, that their proper social function was to manage the transition between the social death caused by impairment and physical death, and that any tensions between staff and residents were best solved by a combination of psychoanalysis, euthanasia, and the imposition of military and colonial governance techniques.

Hunt's (2022a,1972,b) two responses to their work are unrelenting in their hostility and rigor. The second is generally seen by EDR proponents as the genesis of their own contribution to theorizing research practice: proving the demand amongst disabled people for a different way of structuring their relationship with researchers, and providing an analysis of pre-existing disability research as a form of exploitation (see, *inter alia*, Oliver, 1997, pp. 84–85; Mercer, 2002, p. 298; Stone and Priestley, 1996, pp. 702–703). From it, EDR took Hunt's claims that scholarly detachment and value neutrality were simply a screen to legitimate the biases and ideologies of elites and the pet theories of academics (Hunt, 2022b, p. 271); that academics were generally parasitic on the social problems of disability for their career opportunities (and thus uninterested in solving them) (p. 275); and that non-emancipatory research was primarily concerned with justifying the status quo rather than seeking reforms which would improve the lot of participants (p. 269).

Less appreciated (and, as we shall see, frequently contradicted) is Hunt's repeated appeal to the scientific method and norms of objective research; and the constitutive role these played in justifying other elements of his critique. In his initial retort to Miller and Gwynne, Hunt (2022a,1972, pp. 84–88) had complained not only that their work was dehumanizing, but also scientifically shoddy. They had generalized their conclusions from statistical outliers, designed interviews to solicit manipulable responses from participants, and selectively quoted other scholars to give the misleading impression that their assumptions were well-supported in their field. Hunt assumed that if these flaws were evident to him as a layman, they would lead other academics to discredit (or at least

ignore) Miller & Gwynne's work. This assumption was proved false by *A Life Apart's* growing influence throughout the 1970s (Hunt, 2022b, pp. 269–270).

In his second critique (2022b, 1981), Hunt's analysis of why this had happened and how disabled activists should respond was influenced by both his personal intellectual development, and by the changing balance of forces in British disability politics. Analytically, Hunt had spent much of the "70s deepening his engagement with Marxism. In Marx's (1971, pp. 498–522; 1991, pp. 956–957) critique of political economy, he distinguished between the scientific economists of the 17th and 18th Century, and the "vulgar," unscientific economists who dominated in his own time. The former had aimed at accurate descriptions of capitalism's workings and rigorous explanations of its social effects. The latter's role Marx characterized as developing increasingly implausible apologies for capitalism's brutality, and solving trivial efficiency problems for one or another branch of industry.

For Marx, the transition between the two rested on the subsumption of intellectual endeavor to the social relations of capital at the end of the 18th Century. As the bourgeoisie took over the patronage functions of the old aristocracy, they simultaneously assumed control of how research was paid for (by retainer or university employment), how it was disseminated (publishing), and the terms of access to its necessary materials (records, workplaces, etc). To access these resources, intellectuals must prove themselves useful to this bourgeoisie and, importantly, avoid uncovering any unpleasant truths that might impede future investment (such as capital's crisis tendencies). The objective social world investigated by previous economists had not disappeared, Marx argued—and nor had their methods of investigation become obsolete. The social relations of intellectual life had, however, now altered such that this world could not be honestly approached, nor these methods fearlessly used, within the institutions and cultures of intellectual life. Scientific practice could be advanced only by those who decouple their research from the authoritarianism of intellectual milieus; taking their impetus from workers' movements who have no desire to make excuses for the present order, and thus free to face it without distortion.

Hunt (2022b) developed an analogous argument for disability research. Miller and Gwynne had not only agreed the terms for their research with government funders; but, by virtue of undertaking their project, had entered a highly competitive market of "experts" qualified to advise the state and service providers on the management of disability services and policy transitions. States and providers have strong policy commitments, based on their previous practice and the distribution of power within them. If the scientist tells them what they want to hear, or provides recommendations which they would like to implement; the rewards can be lucrative. If the scientist discovers inconvenient facts (that these policy preferences are falsely premised and dishonestly justified), they're likely to exit the market promptly (pp. 277–278).

It was pandering to such preferences at the expense of scientific investigation, in Hunt's estimation, that led Miller and Gwynne to accept that physical impairment caused social irrelevance, and that authoritarian segregated services were its necessary corollary (p. 274). By contrast, disabled people themselves have no such material incentives to inhibit scientific practice:

“Faced with any socially oppressed group, social scientists have a choice of only two alternatives: either a firm commitment to serve the interests of the oppressed group to end their oppression, or a commitment to serve the interests of the oppressors to continue their oppressive practices (which last they also do by serving their own interests). There can be no middle way.

In the first instance a scientific approach remains possible, i.e., objective reality can be looked at, and science can be placed at the service of the oppressed group to help them free themselves. In the latter instance a scientific approach is not possible, objective reality cannot be examined straight but can only be distorted. (...) It is commonly believed that commitment to the cause of an oppressed group means that “reality” will be ignored or distorted, and therefore that the best scientist is the one who tries to be least involved and most detached. Nothing could be further from the truth, as *A Life Apart* illustrates. It is precisely those who try to take a detached view of oppression who cannot be objective.” (p. 275)

The political factor which influenced Hunt’s account was the emergence of an independent DPM: capable of taking advantage of disabled people’s ability to view the world objectively by aggregating collective experience to direct research, evaluating its processes and findings, and acting on its conclusions. Where Miller and Gwynne rejected calls to objectivity (claiming that social science should aim only at improving efficiency, not a true explanation of the world) (in *ibid*, p. 272), this movement was:

“enabled to view reality objectively, recognizing the potential [for liberation] that has now been made possible and by contrast the oppressive conditions of life that we are forced to put up with. The important thing is that our approach maintains a scientific analysis of our situation, which examines segregated institutions objectively within the context of modern social developments, [and which] is both necessary and possible.” (p. 268).

Hunt’s conception of what this “scientific analysis” consists in was fairly traditional in its philosophy. Hunt offered two core principles for the kinds of research practice that the DPM should demand: Firstly, all investigations should accept external criteria of falsification⁷ and evaluation. Any conclusion reached by (academics’ or disabled people’s) intellectual practice should be open to contradiction by lay disabled people’s observation of the world around them. With this principle, disabled people could test the legitimacy of research, and establish whether its findings were solid enough to inform their political strategies. Without it, intellectual pursuits would be “about as scientific as magic” (p. 272).

The second, only slightly more ambitious (and influenced again by Hunt’s Marxism) was that research must capture the relationships between the material effects of social phenomena in

a state of flux and tension. Disabled people’s emancipation projects occur in a changing social world, characterized by economic and political struggles, and where actions are liable to lead to unexpected consequences when they are not informed by the most nuanced analysis possible. The variables necessary for such an analysis are not captured by the limited experiential standpoints occupied by the members of an oppressed group. The function of science, for Hunt, is to uncover the determinants of disablement which elide the lived experience of being disabled:

“Oppressed groups have nothing to lose, and everything to gain, from the most precise and thorough understanding of the situation we are struggling to change. To change our oppressive reality, we cannot afford to leave out of account any significant factor in the situation: to do so necessarily means defeat (...) A scientific approach must look at a part in relation to the whole, or institutions in relation to the society in which they exist. It must look at social forces as in a state of movement and development, not as being static; and, therefore, it must look at institutions in the context of a changing society. It must also look at the struggles of people for change in relation to the material and social changes that have taken place in the society, not as mere reactions to irreversible natural causes” (p. 276).

5 Emancipatory research and the turn to subjective experience

If Hunt had been “pioneering” in his analysis of the tensions between disability researchers and disabled participants (Oliver, 1997, p. 84); his proposals to reform this relationship were less convincing. Hunt recognized that academic researchers had skills which the movement needed as well as perverse incentives, but died suddenly before finishing his second critique. He left a draft questionnaire (2022b, 1981, pp. 282–4), which he had expressed grave reservations about to his comrades, to gauge the political commitments of any academic approaching the movement for research participants. This prescription was manifestly insufficient given the diagnosis he had made. Hunt had shown that researchers’ incentives and preferences were likely to change throughout a research process, but his solution was merely to filter some explicit preferences out at its earliest stages.

Later emancipatory researchers attempted to correct this gap between analysis and action, and develop “a methodology and set of techniques commensurate with the emancipatory research paradigm” (Oliver, 1992, p. 112). It is in their work of the 1990s that the technical innovations most conducive to solving the CCP are theorized, implemented, and reported as examples for future practice. Operational suggestions are advanced to decentralize control of researcher decisions across project stages—from design, to data collection, to evaluation (Priestly, 1997); formative evaluation criteria are formulated for participants to assess if a project is amenable to their control (Zarb, 1992, pp. 128–129); and multiple strategies for user-direction are developed for instances where funding arrangements and logistics prevent stakeholders’ direct supervision of the researcher (summarized in Mercer, 2004). This infrastructure should have had a positive effect

⁷ The word Hunt uses here is “verification”; reflecting lay understandings of the philosophy of science current when he was writing. I have altered the term here as the passage I paraphrase is concerned with disabled people’s ability to falsify, and thus dispense with, incorrect conclusions.

on bringing participants and researchers together. The framework developed in the literature did a great deal to align the expectations of participants (who could see what the research process might entail and their leverage in it) and researchers (who were given clarity on their obligations in EDR).

Simultaneously, these scholars altered profoundly the analysis on which the initial demand for research had been made. Hunt (2022b, p. 272) had argued that it was disablist “bias” which leads “to a project totally lacking scientific validity.” EDR proponents claimed the exact opposite: that even the pretense of scientific validity, and the realist ontology on which it rests, directly caused disabled people’s dehumanization—sometimes citing unrelated passages from Hunt to justify this claim⁸. Instead of a great leveler, which allowed disabled people to evaluate and act on research findings, claims to objectivity were seen as no more than an “ideology” (Zarb, 1992, p. 130); “falsely premised” on oppressive social relations (Priestly, 1997, p. 90), and invariably justifying the right of a “relatively small group of powerful experts [to] work on a larger number of relatively powerless research subjects” (Oliver, 1992, p. 106).

The fundamental problem with previous disability research was seen not as its failure to increase disabled people’s understanding and capacity for action; but that its descriptions alienated them from their senses of self and distorted their life-experience. The emancipatory response was to proclaim fidelity to both: focussing on the “symbolic world in which the subject lives” (Barnes, 1992, p. 116) and the “meaning of events [from participants’ perspectives] not their causes” (Oliver, 1992, p. 106).

There is little evidence that this focus on subjective meaning-making was much in demand: either by organizations in the DPM, nor disabled lay people who become research participants. The research projects commissioned, managed, and distributed by movement organizations indicate a demand for research practice which mirrors Hunt’s insurances on analyses of social processes and principles of external falsification (albeit absent his Marxist meta-theory). Despite its author’s later claim that it constituted the paradigmatic instance of EDR (Barnes, 2004, n.p.); Barnes’s (1991) study of discrimination in Britain (commissioned and supervised by a national DPO) shows little sign of abandoning objectivity or causality, nor reconstructing obscured subjectivities. Instead, the movement instructed Barnes to evidence discriminatory institutional practices across various social spheres (education, employment, leisure, etc), determine the causes of these practices, and deduce the material impacts of proposed or actual government policies on them (p.62).

Other movement-managed research shows a similar orientation toward rigorously examining impersonal social causes. Movement organizations commissioned Macfarlane and Laurie (1996) to examine the relationship between deinstitutionalisation policies and the provision of accessible housing, and Zarb and Nadash (1994) to determine the likely costs of the DPM’s proposals for community support relative to existing forms of “community care”. Those instances where movement organizations allowed

their researchers to deal more substantively with the personal experience of disablement are outliers, and justified by specific project aims rather than the inherent value of personal standpoints as a source of knowledge. Oliver et al.’s (1988) extensive interviews with spinally injured people, for example, responded to the extreme variation in services and living situations around the country, and the fact that “[t]here was little prior work on which to build”. Considering this, in-depth discussions of personal experience were the most reliable source of objective and quantitative, as well as qualitative, data (pp. 7–8). It is clear from this engagement that DPM actors were keen to work with emancipatory researchers, and took full advantage of the opportunity to control more of the research processes, but encouraged EDR practitioners to leave their anti-objectivity commitments at the door to pursue knowledge that the movement couldn’t source from within its own ranks⁹.

EDR practitioners have, regrettably, seldom reported evaluations of their practice by disabled participants outside of movement organizations. Where they have, however, participants appear to be largely ambivalent on the value of reproducing their unalienated experience for academic papers or research reports. Gabutt and Seymour (1998, pp. 8–9) report that, in a project where participants were asked to use their personal experience of disablement to code interviews with professionals, participants were initially keen to talk together about their life histories and personal responses to the data. As the project progressed, however, roughly four-fifths of the participants were disengaged at any one time; with one participant expressing doubt that the project’s focus displayed “the will to bring about change” (p. 9). While representing their own life experiences to their peers appears to have been a self-motivating good for most participants, the promise of a researcher faithfully reproducing it again for others was insufficient to secure their long-term collaboration.

One of the rare recent projects to invoke EDR as a paradigm (Liddiard et al., 2019) provides further evidence, in the form of a dog which refuses to bark, of participants’ limited demand for researchers reconstructing their identities and experience. The academics working on the project began from the theoretical commitment that disabled people are “DisHuman”—complex assemblages of bodily and phenomenological states which elide and reject distinctions between humans, animals, and technology (p. 1049). They soon discovered, however, that lay “co-researchers” strongly believed themselves to be human beings. This was explained as an understandable life-strategy reflecting participants’ marginalized position. If societies ascribe status and recognition to those categorized as human, it is natural to claim membership of this category when one is afforded neither. Such claims, however, were analytically secondary. The fact that *some* data about

⁸ See, *inter alia*: Stone and Priestley, 1996, pp. 702–703; Priestly, 1997, p. 91; Barnes and Sheridan, 2007, pp. 239–40.

⁹ There is some evidence that this preference is not exclusive to the British DPM. A review of disability research across Southern Africa commissioned by the Southern African Federation of the Disabled concluded that the most immediate task for academics and DPOs was to encourage research outputs that could be acted on by disabled activists (Mckenzie et al., 2014, pp. 740–42).

participants could be interpreted as consistent with the DisHuman thesis justified its continued deployment in theoretical descriptions of their lives. Put bluntly, the academics knew better than the lay-person how to analyse the latter's identity, up to and including ascribing their species. Participants were DisHuman regardless of whether they considered themselves so (pp. 1050–1051). The fact that participants neither insisted on reversing this conclusion through available negotiating mechanisms¹⁰, nor withdrew if this proved impossible, implies that they didn't require the research to validate or faithfully represent their experience. Clearly, participants saw something of value in their continued engagement, and tolerated alien descriptions of their lived experience in pursuit of it.

6 Conclusion: re-emancipating disability research

The hypothesis I have offered is that EDR failed to either generalize across disability research, nor contribute consistently to improving disabled people's lives, because its focus on subjective experience and rejection of objectivity and the scientific method clashed with what a sizeable number of disabled people wanted research to do. I have evidenced this by outlining a sustained demand by movement actors for rigorous research on social phenomena that cannot be reduced to subjective meaning-making, and by indicating ambivalence toward EDR's research focus from participants more widely. By reframing EDR as a solution to non-credible academic commitments, I have problematised other explanations of the same phenomenon; indicating that these merely describe EDR's underwhelming progress rather than identify its causes.

I have, hitherto, avoided giving anything like a positionality statement. Like Hunt and Marx, I suspect that personalized data-points are the least useful for rigorous argumentation. As I believe I have shown that my position on research is not wholly idiosyncratic, and in the hope that the observations which spurred this argument might also be relevant to thinking about research differently, I offer the following as a coda.

In addition to my academic research in disability history—supervised by a Steering Group within a movement organization—I hold positions of responsibility in two Disabled People's Organizations (DPOs) at the time of writing, and have previously been commissioned to run a research project at another. I and my comrades are frequently approached (usually by keen PhD students) to become partners on research projects. While the level of control offered to us varies, the emphasis on reproducing the authentic voice of the disabled people we work with is pretty constant across these approaches.

I have two concerns whenever such research is mooted. The first is skepticism that it will tell us anything we don't already know, or provide our members with something they don't already own. We are in touch with the same people the researcher is asking us to

facilitate access to. If we need to ask their experience of something (and they've likely told us their views forcefully already), we can do so without the aid of intermediaries. Similarly, members of our networks can already represent their own experience and identities at very low cost. Blog posts and social media profiles, and before them movement “zines and newspapers, allow disabled people to say whatever they want to an audience larger than most academic journals” readership. Experience and voice, like culture, are things people already have and cannot be given to them. It flatters no-one to make a virtue of wrapping them up as if they were a gift (Sivanandan, 2005, n.p.)¹¹.

The second is logistical. Entering partnership on a research project diverts a lot of organizational resources. At bare minimum, we will have to assign one member to read and comment on extensive drafts, cultivate enough knowledge of the subject area to properly monitor the researcher's practice, and condense the research content and progress to report back to other members. Depending on the research, the actual commitment could be much greater. Our member is constrained from taking part in all the other work the DPO needs them to do while the research is ongoing, and the rest of us must divide their share amongst ourselves. This is a sacrifice worth making *if* the research is likely to give us information we need to further the liberation struggle, or if the process will help our member develop research skills we can use for other purposes. If it doesn't, it is simply a bad investment.

These concerns can be addressed by making emancipatory research about disablement—the economic, social, institutional, and environmental factors which shape the lives of people with impairments, mental distress, or neurological difference—rather than some aspect of disabled people themselves. Realistically, any impetus toward this must, in the short term, come from the academy. The DPM (in Britain at least) is small and cash poor. It is in no position to commission large research projects in line with its needs, nor to exert the same leverage in negotiations with researchers that it could in the '90s and 2000s—which likely makes some organizations reticent about agreeing to research partnerships. If we are to save what is good from EDR—its emphasis on empowering subjects and its democratization of research practice—it is necessary for the academics who pitch most disability research to attend to the external factors which prevent disabled people from enjoying the same freedoms as their peers.

¹¹ While a detailed analysis of Feminist Disability Studies is out of this article's scope, my argument here suggests that some of its premises may be ill-conceived. If the role of feminist disability research is to ‘allow space (...) for the absent subject’ (Morris, 1992, p. 159), or ‘retrieve dismissed voices’ (Garland-Thomson, 2005, p. 1557); the theorist must explain the productive role of academic research in ending this marginality. My contention is that the dismissed may not be so absent as is asserted, and may have more powerful tools at their disposal than those offered by academicians. For an alternative view of the relationship between feminist and disability politics (and consequently research), see Rae, 1996.

¹⁰ The project had a formal participants' council, although its exact powers are unclear (Liddiard et al., 2019, p. 1038).

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Crippling auto-/ethnography?

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Given the crisis of representation (of *the other*) and complicated histories of othering, ethnography seems to be a methodology in need of crippling. Autoethnography, then, is one approach to solve said crisis of representation. Down to classics like Robert Murphy's *The Body Silent*, Disability Studies often use authors' autobiographical experience in a way that may be called autoethnographic. However, Disability Study's authors rarely engage with methodological literature on autoethnography. Moreover, autoethnographic literature frames *The Body Silent* and others as first-person illness narratives, which I read as one indication that autoethnography might play into a *tragedy* narrative of disability. This paper tries to think through what it can mean to cripp auto-/ethnography. To this end, I introduce crippling as an emancipatory strategy that promotes changing how one feels about disability and gather previous attempts of crippling academic knowledge production, which specifically center ableist temporal and emotional norms. In a second step, I outline ethnography and autoethnography as methodologies of interest and elaborate, which methodological development could be harnessed for crippling and in which ways both could benefit from further crippling.

KEYWORDS

cripping, crisis of representation, ethnography, autoethnography, disability studies, ableism in academia, ableism, illness narratives

1 Introduction

This conceptual analysis asks the question what it would mean to cripp ethnography and/or autoethnography. Crippling is an emancipatory strategy discussed in research and activism whose proponents call for a re-evaluation of one's feelings regarding disability toward the affirmative (McRuer, 2006). I explore the possibilities of a crippled auto/ethnography here based on the design for a planned post-doc project on affective resistance to accessible open space planning. Within Disability Studies the emerging sub-field of "critical access studies" (Hamraie, 2017, p. 13) investigates why (demands for) accessibility fail to realize an inclusive society via architectural and technological design. Several authors discuss affective resistance to accessible design (Siebers, 2009; Titchkosky, 2011; Fritsch, 2013) and some authors specifically report on affective resistance to an accessible design of open spaces as well (Clare, 2015; Kafer, 2017).

As I have argued elsewhere (Wechuli, 2022), writing about affect and emotion in Disability Studies can focus different aspects. One of those aspects are affective reactions to disability, which tend to be discussed as socio-culturally shaped projections yet remain undertheorized to date.¹ Knowledge production here is usually based on observations of the strange behavior of able-bodied people toward disabled people, which Disability

¹ I argue for an understanding of emotion, affect and feelings as socio-cultural phenomena (Ahmed, 2014; Wetherell, 2012; Scherke, 2009) that have political functions (Ahmed, 2014) as well as social and cultural origins and impacts (Scherke, 2009; Wetherell, 2012). From this perspective, affective reactions to disability require an explanation (Scherke, 2009; Hughes, 2012).

Studies explore either autoethnographically or on the basis of qualitative data. In a second step, authors apply psychoanalytical, sociological or philosophical theories to reflect on the assumed emotional foundations of this strange behavior (Wechuli, 2024). Often, affective reactions are condensed into one single, distinct emotion concept (Scheve and Slaby, 2019), e.g. when Hughes (2012, p. 68) reconstructs fear, pity, and disgust as “the major—though not the exclusive—building blocks of the emotional infrastructure of ableism”.

To justify an empirical approach to affect, I draw on Sauerborn and Albrecht's (2024) understanding of affectivity for the social sciences that differs from a concept of affect that is partly common in cultural studies, which frames affect as a phenomenon that cannot be grasped in language at all. They identify three characteristics of affectivity that enable empirical research to this elusive phenomenon, namely that it can be observed, narrated and experienced. That affectivity is observable suggests ethnography as a methodology whereas autoethnography seems fitting to capture experience (Sauerborn and Albrecht, 2024).

In the following, I will introduce crippling as an emancipatory strategy (Section 2) and share previous reflections on a crippled knowledge production from Disability Studies (Section 2.1). Then, I will give an overview of ethnography (Section 3) and autoethnography (Section 4) and elaborate entry points to crip these methodologies as well as central critiques. Lastly, the potentials and pitfalls of crippling auto-/ethnography are discussed in conclusion (Section 5).

2 Crippling

“Crippling” (Sandahl, 2003) stands in the tradition of older calls for an affirmative re-evaluation of disability as a source of pride (see e.g. Corbett, 1994; Campbell, 2009; Clare, 2015). The pejorative term *crip* (*cripple*) emerged from activist contexts where the term has been reappropriated despite, or perhaps because of, its history of pejorative use (Johnson and McRuer, 2014b). “[W]ords to shock, words to infuse with pride and self-love, words to resist internalized hatred, words to help forge a politics” (Clare, 2015, p. 84). A reference to *crip* thus proclaims pride by accepting the ascribed social identity without accepting the associated devaluation (Clare, 2015). Reappropriated pejorative terms can draw attention to shared hurt feelings and marginalization and at the same time cause deliberate irritation (Mingus, 2011). Despite the associated hopes of gaining allies for a political agenda, the recycling of terms infused with negative associations remains a complex process (Liddiard and Slater, 2018)—an emotionally complex process as Alison Kafer (2021, 415; her italics) elaborates:

“I remain deeply attached to *crip*—as a word, an orientation, an affiliation, a feeling. [...] And yet, the fact that I love the feel of the word across my skin, the sound of it on your tongue, doesn't change the fact that the word has edges and edges bind”.

Crippling is often used as a verb, for instance in the description of this research topic, which calls for—among other

aspects—cripping research methods, research practices and modes of analysis, in the same way that several authors in disability studies have argued for a crippling of professional standards such as the rules of academic knowledge production (see Section 2.1). Beyond academia, one can seek to crip different areas of life such as sexuality and intimacy (Liddiard, 2018) or family life (Goodley and McLaughlin, 2008; Goodley and Runswick-Cole, 2013) or aspects of disability experiences such as pain (Sheppard, 2020b), or even physical concepts such as time (Samuels, 2017; Kafer, 2021).

Crippling aims to strategically reorient one's (emotional) associations with disability in the sense of “ways of knowing and feeling disability” (Parrey, 2020, p. 37) and learning to feel *differently* about disability (Corbett, 1994). How do disabled people and their allies achieve this reorientation? In order to learn to feel differently about disability, crippling invites the celebration of disability as difference—specifically by re-evaluating even seemingly negative aspects of disability experiences as spaces of possibility. For example, pain can be affirmed as constitutive of being alive (Mintz, 2011), as offering an occasion to focus one's attention or to take a break (Scheuer, 2011). People living with chronic pain may find pleasure in inactivity (Sheppard, 2020a) or new temporal norms (Gould, 2017). In general, many scholars and activists particularly value the potential of Disability Arts to convey an affirmative image of disability (Siebers, 2009). Moreover, Disability Studies make disability a majority issue by framing able-bodiedmindedness as only ever temporary (Zola, 1993; Davis, 2002). “Unless we die suddenly, we are all disabled eventually. Most of us will live part of our lives with bodies that hurt, that move with difficulty or not at all” (Wendell, 1989, p. 108). Crippling not only promotes an affirmative re-evaluation of disability but also provides a rationale why one should feel proud of disability, namely due to disability's potential to subvert norms. This subversive potential has been formulated in detail for norms around interconnectedness and desire (Wechuli, 2022).

As I have argued elsewhere (Wechuli, 2022), crippling as a strategy entails certain benefits but also costs that include emotional costs. In general, affirmative reappraisals counteract *tragic* notions of disability and promise solidarity. Advocates of crippling describe the expected benefits of this strategy as a radical transformation in the sense of collectively imagining otherwise (Anzaldúa, 2012). Affirmative re-evaluations of disability are justified here by the fact that disability has the potential to subvert compulsory able-mindedness (McRuer, 2006) as Liddiard (2018, p. 37–38) explains with regard to a crippled sexuality: “Assimilation is never the goal; ‘passing’—performing normal—is counterintuitive. Crip doesn't seek to normalize or individualize disability or desire, but seeks to draw upon and center its very queerness as a moment of reflection”.

These endeavors are based on an idea that had already emerged in the discourse around Disability Pride, namely to use the lived experiences of disabled people to formulate emancipatory values and norms (Longmore, 1995).

“Beyond proclamations of pride, deaf and disabled people have been uncovering or formulating sets of alternative values derived from within the deaf and disabled experiences. [...] That analysis needs to be made not just because majority values are impossible for people with disabilities to match up to, but

more importantly, because they have proven destructive for everyone, disabled and nondisabled alike” (Longmore, 1995, p. n.p.).

Thus, crippling seeks to generate emancipatory knowledge—for everyone—based on disabled people’s lived experiences by questioning ableist ideals such as beauty, independence, individual achievement or self-control (Goodley, 2014). Interdependence, interpersonal connection and community are examples of alternative values as mentioned by Longmore (1995), which are intended to replace unattainable ideals (see also Goodley, 2014).

As a strategy, crippling is also associated with certain costs. Most prominently, crippling has been understood as elitist endeavor at the expense of disabled communities. Older disabled people, who make up the majority of disabled people in (aging) industrialized nations—just as the concept of *temporary* able-bodiedness suggests (Zola, 1993; Davis, 2002)—rarely identify as *crip*. “Approximately half the people affected by disability are older people, and they are less likely to identify as disabled, let alone to deploy the term ‘crip’; for them, illness and impairment are naturalized as part of getting older” (Arciul and Shakespeare, 2023, p. 26). Such allegations of being unsolidary (Wechuli, in print) were prominently brought forward against the notion of “cripistemologies” (Johnson and McRuer, 2014a)—a neologism that combines *crip* with *epistemology*. Despite the authors’ intention to draw attention to exclusion, their avant-garde terminology was read as an exclusionary, fashionable yet inaccessible term (Johnson and McRuer, 2014b).

Moreover, proud affirmations do not feel equally available across all embodiments, experiences and etiologies of disability (Clare, 2015; Price, 2015; Kafer, 2021). Disabled people who struggle with the impairment effects (Thomas, 1999) describe that it can feel almost impossible cultivate pride in disability. “I am not entirely sure I could ever wear a Proud-To-Be-Disabled T-shirt” (Meekosha, 2000, p. 814). Any celebration of a *crip* coming-out implies a sense of choice and control over one’s embodied experience that unreliable bodyminds may not grant. Involuntary disclosures of one’s disability status instead trigger feelings of shame and fear, which make it difficult to feel only or even *simply* proud in relation to disability (LaCom, 2007). Pain, as another example, complicates the (vague) demand to desire disability (Price, 2015) as does any traumatic history of impairment acquisition respectively the recognition that some ways of becoming disabled are unjust. “What comes after trauma? Can *crip*? Or does *crip* as radicalized stance, as community affiliation, feel less available, less useful, less hopeful to those disabled through violence?” (Kafer, 2021, p. 423). Similarly, theorizations of the subversive potential of *crip* time may differ from lived experiences (Kafer, 2021; see also Samuels, 2017). “[A]ctually inhabiting such temporalities may not feel good; theorizing the transgressive possibilities of *crip* time and living in *crip* time may bring different affective responses” (Kafer, 2021, p. 429).

Crippling as an emancipatory strategy unfolds a tension between subjective and political needs, possibilities and consequences. As feelings cannot be changed at will, expectations of pride can have an exclusionary effect (Schmechel, 2022). “Body politics or queer politics are always politics of emotion as they are about who has the right to feel certain feelings, and which

feelings are required in order to belong to a certain community” (Schmechel, 2022, p. 155). At once, even critics do not deny the political significance of a deliberate emotional re-evaluation of disability toward the affirmative for socio-cultural change (Watermeyer, 2009). A more inclusive understanding should at least acknowledge that feeling proud of disability may be difficult to achieve (Campbell, 2009; Clare, 2015; Sheppard, 2020a) and may be complicated by lived experiences such as pain or violent and socially unjust etiologies. Furthermore, a more accessible approach to crippling should practice a continuous rethinking of its terminology.

2.1 Crippling academic knowledge production

Crippling has the potential to initiate reforms in knowledge production, as it may challenge ableism in academia. In the following, I outline what proponents of crippling have previously written about ways to *crip* research. Centrally, they argue to attend to *crip* time, one’s own emotionality and—related to both—self-care.

Ableist academic orientations are intimately related to temporal norms—a normalization of overwork, and a culture of perfectionism rather interested in the end-product than the work process (Leigh and Brown, 2020). Consequently, claims for “*crip* time” (Kafer, 2013, p. 25) hold substantial subversive potential (Kafer, 2013, 2021; Bê and Sheppard, 2023; Sheppard, 2020b; Samuels, 2017) in academic knowledge production. “[T]heories of *crip* time also highlight how people are refusing and resisting those very expectations, thereby creating new affective relations and orientations to time, temporality, and pasts/presents/futures” (Kafer, 2021, p. 428). Denouncing normative time frames—either deliberately or based on one’s needs e.g., to take time for breaks seriously—can promote wellbeing, a pleasurable engagement with one’s body or consciousness for the present tense (Samuels, 2017; Sheppard, 2020b; Liddiard et al., 2019). As editors of a special issue on representations of chronic illness in Disability Studies, Bê and Sheppard (2023) denounced normative time frames in the publishing process for the sake of *crip* time by considering potential phases of sick leave from the onset.

“We sought ways to make our practice as academics inclusive, while acknowledging that we are ourselves restricted by the structures imposed on us by academic institutions; a part of that was making time to *be ill*, to acknowledge that those times would not necessarily be predictable” (Bê and Sheppard, 2023, p. 137; their italics).

Similarly, Liddiard and Watts (2022) report on a participatory research project that rethought normative schedules for qualitative research in order to make time for self-care. In their experience, this changed approach to temporality greatly increased accessibility for young disabled co-researchers.

“I feel working in this way has enabled me to contribute more to the project as I’ve been able to do it when I feel well enough rather than forcing myself to do something when my

mind and body are screaming no. This has kept my love and enthusiasm for the project high” (Liddiard and Watts, 2022, p. 40).

Johnson and McRuer (2014a) frames a prioritization of her wellbeing and self-care over work and family commitments rather as act of *crip willfulness* (Ahmed, 2010) than in temporal terms, yet describes similar outcomes.

“I am not *unable* to travel; I am frequently *unwilling*. The inter-implications of capacity and debility have led me to this place of *crip willfulness*, which sounds like a mean place of stubborn resistance, but feels like a calm relinquishing of fantasies that I can force things (situations, bodies, emotions, sensations) to be other than they are. It is a refusal to insist—a refusal to act in accordance with the system of compulsory able-bodiedness—that requires individuals to mask, suppress, and disregard discomfort in the process of determining what is possible, of what we are capable” (Johnson and McRuer, 2014a, p. 136; their italics).

Johnson and McRuer (2014a) describe an academic knowledge production that prioritizes self-care and mutual care over competitive orientations toward sensational research results as “*cripistemologies*”² in the sense of *cripped epistemologies*—“[t]he tension between a long-standing *cripistemological* yearning to attend patiently, carefully, and collectively to varied sensations, on one side, and, on the other, the neoliberal compulsion to get better and to be better/sensational/exceptional...” (Johnson and McRuer, 2014a, p. 138).

Besides an application of *crip time* in academia, several authors discuss the place of emotionality in research. Price and Kerschbaum (2016, p. 33) challenge expectations of emotional detachment in qualitative methodologies: “Why does so much qualitative-methodology literature give the impression of emotional calm on the part of the researcher?” They argue that emotional involvement based on researchers’ own experiences may contribute to deepen understanding—in their specific example on the importance of accessibility. Qualitative methodologies can, thus, gain from considering disability as an integral rather than a disruptive factor from the beginning of the research process. Stephanie Kerschbaum reports not only an ease to conduct and analyze interviews but also an intense emotional, joyful reaction to this ease facilitated by a use of sign language.

Similarly, one can state ableist expectations of emotional detachment in scientific presentations (Donaldson and Prendergast, 2011; Gunaratnam, 2021)—even though presentations and their preparation are a common source of anxiety (Gunaratnam, 2021). In their editorial to a special issue of the *Journal of Literary and Cultural Disability Studies* entitled “There’s no crying in Disability Studies”, Donaldson and Prendergast (2011) reflect on their joint experience of breaking such expectations by crying during their conference presentations.

“Emotion and the expression of emotion are also gendered in significant ways. Tears are feminine, and hence trivialized. Crying during a conference presentation is in one respect a failure to regulate the emotions. It signifies a moment of vulnerability that threatens to undermine the authority of the speaker and, further, in this particular case, it appears to resuscitate the pity narrative that undermines disability rights. On the other hand, crying at a conference presentation is a transgression that foregrounds issues central to both feminism and Disability Studies in potentially productive ways. Our bodies, and our minds, do not always conform to prescribed norms and regulations. Crying when one wishes not to cry is both a bodily refusal and an inability to contain or to be contained by these rules” (Donaldson and Prendergast, 2011, p. 130).

Expectations of an emotionally detached presentation style ultimately reproduce a binarization that positions researchers as *able-minded*—even in research on mental health. Beyond emotional detachment, there are many unwritten conventions in academic conferences as pointed out by neurodiverse presenters who feel pressured to minimize their difference. Such conventions—how to present, how to ask questions, how to respond to (challenging) comments, how to socialize—can make conferences inaccessible (Gunaratnam, 2021).

To *crip* ableist presentation styles may translate to asking how a practice of *vulnerable* presentation beyond self-control could look, sound and feel like—a performance that breaks with the expectation of an implicitly *able-minded* presentation (Gunaratnam, 2021). Price and Kerschbaum (2016) read emotional engagement and familiarity with inaccessibility as motivation to make interview settings as accessible and, thus, pleasant as possible for their interviewees. The same could be said for academic conferences—or even the classroom (Fritsch, 2024)—where one can learn from the lived experiences of disabled people (Longmore, 1995) in order to promote wider accessibility.

To sum up, discussions around a *cripped* academic knowledge production, so far, have centered harmful ableist norms in the realms of temporality and emotionality. Disability becomes a (proud) place of possibility by making their harmfulness more obvious and, thus, holds subversive potential to change orientations and priorities. Centering disability can, ultimately, make academia a more livable, caring, solidary and accessible place. Even if framed as majority issue, it remains important to question who can afford to attend to *crip time* in the neoliberal academy.

3 Ethnography

Central characteristics of ethnography are a presence in the field and an attitude of curiosity. Ethnographic research thereby focusses on implicit knowledge and forms of practice (Breidenstein et al., 2013)—or emotional and embodied forms of knowledge (Saukko, 2010), which seems fitting to the research interest described above on affective resistance to accessibility in the design of open spaces as observed by authors of Critical Access Studies (see Section 1). Fittingly, Sauerborn and Albrecht (2024) suggest ethnography as the methodology of choice to capture the observable aspects

² The notion of *cripistemologies* also challenges epistemologies of disability as an object of knowledge (Johnson and McRuer, 2014a), which proved fruitful, for instance, for a theorization of chronic pain based on lived experiences of people living with pain (Sheppard, 2019; Patsavas, 2023).

of affectivity. Ethnography grants quite a bit of methodological freedom and opportunism (Breidenstein et al., 2013)—among them a processual sharpening of the research question and methods (Flick, 2000). The most prominent ethnographic method, participant observations, produces a high quantity of complex data (Breidenstein et al., 2013), which seems equally promising for research on a topic that remains undertheorized (see Section 1).

However, ethnography suffered from the so-called crisis of representation (of *the other*) (Clifford and Marcus, 1986). This crisis challenged “an ideology claiming transparency of representation and immediacy of experience” (Clifford, 1986, 2) and instead acknowledged the co-constructed nature of cultural phenomena through practices of writing, which can ever only depict a partial truth, and does not hold authority to speak for others (Clifford, 1986; see also Said, 1978; Spivak, 1988).

“Ethnography in the service of anthropology once looked out at clearly defined others, defined as primitive, or tribal, or non-Western, or pre-literate, or nonhistorical – the list, if extended, soon becomes incoherent. Now ethnography encounters others in relation to itself, while seeing itself as other” (Clifford, 1986, 23).

In brief, ethnographic research was accused to feed into processes of othering (Harrison, 2020) – even colonization (Fuchs, 2022) – while the possibility to understand *the other* was increasingly challenged. How can ethnography be crippled then?

I argue to combine ethnographic methods with a participatory approach, where e.g., mixed-abled teams jointly or separately carry out participant observations and take individual field notes, which are then analyzed together. From a Disability Studies perspective, participation is to be understood as the cross-cutting issue in the UN Convention on the rights of people with disabilities, which has taken up demands of disability rights movements (Hirschberg and Köbsell, 2017). In ethnography, initial considerations on participatory approaches have been made under the label “collaborative ethnography” (Bettmann, 2022) and with the recommendation that its further development should be more closely linked to methodological discussions in the context of participatory research.

Furthermore, participation may serve as an epistemic moment—following feminist standpoint theories (Flick and Hoppe, 2021). An appreciation of minoritized researchers—and among them disabled researchers—as observation experts for societal relations is not new to ethnography (Breidenstein et al., 2013). Such approaches tie in well with discourses on crippling that postulate the lived experiences of disabled people can be used positively as an epistemological moment, e.g. to reveal social norms that are harmful to all members of society (see Section 2).

Ethnographic research seems attractive to co-researchers since field work is an immersive experience (Breidenstein et al., 2013), which can be more enjoyable compared to e.g. deductive analyses of transcribed interviews. Moreover, ethnographic research seems to offer grounds for participation with its opportunistic and processual character as described above. Such orientations allow for participation in the sense of negotiating and jointly deciding on research questions and methods suitable to the field and the research team—step by step. Moreover, ethnography allows for

polyphony in final texts (Emerson et al., 2001; Saukko, 2010; Clifford, 1986).

However, this time- and energy-consuming research practice (Breidenstein et al., 2013) might clash with co-researchers’ time constraints (Hilscher, 2021; Thompson, 2021). Particularly immersive ethnographic research is described as stressful by researchers (Schmid and Eisewicht, 2022). Besides, any analysis and discussion of discrimination of one’s own community requires emotional resources (Thompson, 2021). An unwillingness to meet such emotional demands should, thus, be considered (Hilscher, 2021; Thompson, 2021)—especially given the asymmetric recognition of co-researchers and researchers for their work (Russo, 2021). In this sense, a confrontation with barriers is discussed as humiliating in itself (Campbell, 2020). Therefore, a crippled practice of collaborative ethnography calls for a careful dealing with co-researchers temporal and emotional resources. Who should participate in which phases of the research process to what extent should, thus be thoroughly considered and negotiated instead of a mere declaration of symmetrical relationships between researcher and co-researchers (Flick and Herold, 2021).

Moreover, the above mentioned opportunism and freedom also means that there is no consensus on methods/techniques (Schmid and Eisewicht, 2022; Breidenstein et al., 2013). Therefore, ethnography is described as a particularly demanding research strategy, that requires researchers to be competent in various ways in order to display openness, flexibility and reflexivity (Breidenstein et al., 2013; Flick, 2000; Fuchs, 2022). Like many other qualitative methodologies, ethnography fosters a circular approach rather than a linear research process from the development of a research question, identification of a research gap based on the state of the art, design of a methodology, data collection and analysis to discussion and dissemination (Harrison, 2020). Therefore, it is more difficult to involve co-researchers only in certain aspects of the research process—if they should prefer so (Breidenstein et al., 2013). Field work usually accumulates an unsystematized corpus of field notes, which are incomprehensible to others (Emerson et al., 2001). Thus, ethnographic research might be specifically challenging to design as participatory or collaborative if the questions are asked whether co-researchers are able *and* willing to participate.

4 Autoethnography

One answer to ethnography’s crisis of representation (of *the other*) (Clifford and Marcus, 1986) is a turn to the personal via autoethnography. Rather than hiding the researcher and author behind allegedly neutral observations and interpretations, personal experience is scrutinized as data (Anderson, 2006). Autoethnography takes serious the feminist claim that *the personal is political* while it understands both as co-constituted by the self and others (Jones and Adams, 2024). Authors seek “exposing a vulnerable self” (Ellis and Bochner, 2000, p. 739) and connect their personal experience to the wider cultural context (Ellis and Bochner, 2000). “Yet the use of personal experience alone does not make a project autoethnographic. Autoethnographers use their experience to describe, and sometimes critique, cultural beliefs, values, practices, and identities” (Jones and Adams, 2024, p. 423).

That said, autoethnography combines ethnographic research – e.g. in the form of fieldwork, artifacts, field notes and *thick* descriptions—with a focus on autobiography (Jones and Adams, 2024; Ellis and Adams, 2020).

“Autoethnography is an approach to research and writing that seeks to describe and systematically analyze (graphy) personal experience (auto) in order to understand cultural experience (ethno)” (Ellis et al., 2011, n.p.). The wide range of approaches subsumed by the term autoethnography (Ellis and Bochner, 2000) can be divided into an analytic and an evocative subgenre (Anderson, 2006). The former seeks to analyze personal experience in triangulation with other data and in dialogue with sociological or cultural science theory (Anderson, 2006), whereas evocative autoethnography “repositions the reader as a coparticipant” (Ellis and Bochner, 2000, p. 744). Evocative autoethnography pursues the dialogic goal to evoke an emotional response in the sense of allowing the reader to empathize with the subject in the narrative to promote a transformative dialogue across difference. Thus, rather than narrating stories *true* to autobiographical experience, evocative autoethnography centers deeper meanings connected to these autobiographical experiences, or verisimilitude. For narrative effects, details may be changed and events collapsed (Ellis and Bochner, 2000). Effective autoethnographies, therefore, engage personal experience with theoretical frameworks or concepts, and offer complex and complicating analyses of these experiences in a narratively coherent way (Jones and Adams, 2024). Autoethnography can be described as post-qualitative research (Aberasturi-Apraiz et al., 2020) that rather seeks to change social reality to the better than describe and accurately document it (Geimer, 2011).

Given such transgression, autoethnography has attracted substantial critique—as narcissistic, quasi-therapeutic exercise beyond research (Ellis and Adams, 2020). According to Geimer (2011), qualitative research across different methodologies relies on a distinction between first- and second-order constructions in the sense of lived experiences and theoretical reconstructions of these lived experiences. In his take, autoethnography does not attempt to generate second-order constructions and, thus, forgoes indicators of rigor in qualitative research. An acknowledgment of autoethnography as qualitative methodology might, ultimately, undermine that qualitative research is taken seriously as collection and analysis of empirical data. However, a blurring of the distinction between art and (social) science is already problematized in ethnography (Clifford, 1986) as is a critique of solipsism (Fuchs, 2022).

Importantly, a focus on the personal does not have to translate to an individualistic understanding of the self. Further developments in autoethnography include relationality in the sense of collaborative witnessing and becoming part of *the other's* story or even autoethnography based on experiences by proxy such as a transgenerational transmission of trauma (Denejkina, 2017). “Perhaps autoethnography is not about the self at all; perhaps it is instead about a willful embodiment of ‘we’” (Spry, 2018, p. 628). Jones and Adams (2024, p. 421) promote a de-individualistic version of autoethnography as “becoming-with”—a relational practices that seeks to establish kinship with other

people, species, environments etc. and ultimately, imagine a more just world.

Autoethnography is an approach to research that reflects a renewed attention to emotions in social and cultural science (Ellis and Bochner, 2000; Anderson, 2006; Jones and Adams, 2024; Geimer, 2011), which is particularly prominent in its evocative subgenre (Anderson, 2006) that is “showing how personal experience offers insight into the emotional, embodied, and relational aspects of culture” (Jones and Adams, 2024, p. 425). Evocative autoethnography foregrounds “what narratives do” (Ellis and Bochner, 2000, p. 746), which seems very compatible with a focus on what emotions do as promoted by theorists of affect and emotion such as Ahmed (2014) or Wetherell (2012).

Prominently, autoethnography features disability as one complex and contingent positionality influencing lived experience (Ellis and Bochner, 2000, p. 735) or (chronic) illness as “emotionally wrenching experiences” (Anderson, 2006, p. 377). Several classics of Disability Studies can be read as autoethnographic, such as Murphy's (2001) *The Body Silent* (see also Anderson, 2006) or Zola's (1982) *Missing pieces* (see also Ellis and Bochner, 2000). Besides, autoethnographic writing often centers epiphanies and existential crises that are framed as rooted in exclusion, discrimination and marginalization (Geimer, 2011). Despite such emancipatory intention, I argue that such framing can play into a *tragedy* narrative that equates disability with a pitiful functional impairment, which is further positioned as the sole explanation for the economic as well as sociocultural exclusion of disabled people. Such an individualization of the social problem disability has long been contested by activists and researchers in Disability Studies (Dobusch and Wechuli, 2020). “Given autoethnographers' critical edge, there is a tendency to tell stories about tragic events and painful experiences to promote awareness and change” (Ellis and Adams, 2020, p. 370).

Nonetheless, one key goal of autoethnography is to make research more accessible (Ellis et al., 2011; Jones and Adams, 2024) and specifically create more accessible texts (Ellis and Bochner, 2000; Ellis and Adams, 2020). More specifically, central proponents of evocative autoethnography argue that more conventional methodologies are inaccessible to minoritized researchers and readers: “For the most part, those who advocate and insist on canonical forms of doing and writing research are advocating a White, masculine, heterosexual, middle/upper-classed, Christian, able-bodied perspective” (Ellis et al., 2011, n.p.).

5 Concluding discussion

A perspective of crippling can counter *tragic* notions of disability and produce emancipatory knowledge for all based on disabled people's lived experiences. Using disability as an epistemological resource may change the rules of knowledge production itself, both in terms of epistemologies about disability—“what we think we know about disability, and how we know around and through it” (Johnson and McRuer, 2014a, p. 130)—and the accessibility of methodologies themselves. This paper has focused on the latter aspect in order to challenge ableism in academia, which can translate to, e.g. questioning normative

time frames in data collection, analysis and dissemination as well as expectations of an implicitly able-minded performance in data collection and dissemination (see Section 2.1). Yet, issues of inaccessibility surrounding crippling itself—as an elitist and potentially exclusionary, emancipatory strategy (see Section 2)—should not be forgotten. More inclusive notions of crippling acknowledge the difficulty of proud revaluations of disability across difference and revise their terminology for the sake of accessibility.

Given the crisis of representation (of *the other*) (Clifford and Marcus, 1986), ethnography can benefit from crippling in order to develop less othering research practices. I argue that ethnography's appreciation of minoritized researchers as observation experts (Breidenstein et al., 2013) and its concession of polyphony in final texts (Emerson et al., 2001; Saukko, 2010) offer entry points for crippling. Collaborative ethnography (Bettmann, 2022) seems to be a promising extension of ethnographic approaches that might even be considered a way of crippling while ethnography's time and energy implications may conflict with temporal norms in an ableist academia, which already disadvantage disabled researches (see Section 2.1). Similarly, the complexity of this research approach limits its accessibility (see Section 3). In other words, a crippled ethnographic design should center accessibility for a range of researchers and readers and foreground—and defend according to Harrison (2020, p. 350)—the slow modes of research the ethnographic tradition stands for: “[P]atience and attention to human complexities are under threat by assembly line modes of academic production that treat time and knowledge as commodities.” From this angle, ethnography can support claims for crip time.

Autoethnography and, particularly, its evocative subgenre developed a different answer to said crisis of representation (see Section 4). This methodology prominently features disability and focusses accessibility (Ellis and Bochner, 2000). Down to its classics, Disability Studies seem open to such an analytic use of autobiography to further an understanding of disability experiences in their cultural context. I argue that Disability Studies could largely benefit from a deeper and more systematic engagement with autoethnography. Evocative autoethnography seems to offer a

particularly promising way to de-individualize (Jones and Adams, 2024) and collectivize experience. However, autoethnography risks feeding into a *tragedy* narrative of disability—not least since Disability Studies classics are framed as illness narratives (Anderson, 2006) rather than as analysis of disability as a social problem.

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Crippling inquiry: breathing life into co-produced disability methodologies

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Introduction: Our contributions within this article emerge from our experiences of co-leading a new Wellcome Discovery Award funded project, *Crippling Breath: Towards a New Cultural Politics of Respiration*. As a diverse team of clinicians, artists, academics and others with lived and embodied experience of disability, chronic illness, and neurodivergence, we are broadly exploring breathing and ventilation (e.g., forms of medical technology that support respiration) through arts-informed, archival, narrative and ethnographic research approaches.

Methods: Crippling Breath aims to forge new understandings of respiration from crip perspectives, which unapologetically center disability as a valued human experience. In this article, we unpack the meanings, politics and practices of crip perspectives and methodologies – forms of knowledge production that emerge from lived and embodied experiences of disability and chronic illness – and consider their contributions to our project so far. We think through crip time, Slow scholarship and (seemingly) radical things like rest and recuperation, and grief and loss within the research process.

Results: We share the importance of embracing flexibility, adaptability and radical care as routine across our team, because we all bring various types of impairment, embodiment, chronic illness, and caring responsibilities.

Discussion: We question the meanings of these forms of *welcoming in* disability, impairment and difference as ways to develop radical and cripcultures of co-produced and innovative disability research methodologies, and conclude by calling for a more inclusive sociology.

KEYWORDS

co-production, crip, ventilation, illness, care, embodiment

Introduction

Crippling Breath: Toward a New Cultural Politics of Respiration is a 5 year transdisciplinary program of research funded by the Wellcome Trust. It centers and explores the lives of people who have had their lives saved and sustained by ventilatory medical technologies. Centring arts-informed, archival, narrative and ethnographic approaches, Crippling Breath develops crip

perspectives - forms of knowledge production that emerge from lived and embodied experiences of disability and chronic illness. Academics, researchers, experts-by-experience, clinicians and artists are working in collaboration to co-curate and co-produce new understandings of the experiences of ventilated people, across a host of identity positions, to interrogate the new cultural politics of respiration and ventilation in a continuing global pandemic, and as we imagine post-pandemic futures. *Crippling Breath* centers a range of methodological approaches to explore the experiences and meanings of living on forms of ventilation. To clarify, when we talk about ventilation, we are referring to non-invasive forms of ventilation such as Continuous Positive Airway Pressure (CPAP) or Bilevel Positive Airway Pressure (BiPAP) technologies; but our project is also seeking to explore invasive forms of ventilation, such as a tracheostomy or intubation during times of (respiratory) crisis. Our focus on ventilatory technologies pulls into view a range of people from different kinds of impairment and illness categories: people with neuromuscular impairments and associated respiratory illness; people with acquired respiratory illnesses (such as Chronic obstructive pulmonary disease: COPD); people with respiratory failure; and people who may encounter ventilation on the trajectory of other forms of progressive illness, such as Motor Neurone Disease (MND). We want to know: (i) what new forms of scholarship are needed to radically transform understandings of respiration and ventilation; (ii) how we can better understand the social, cultural, political and material meanings of ventilation and breathing during an ongoing global pandemic, and as we imagine post-pandemic futures; and (iii) whether we can propose the ventilatory experience as a space to promote new conversations about life, death, disability and health. Further, we want to know, (iv) about the kinds of affective, relational and intimate relations that may be engendered in and with the medical technologies that sustain and save the lives of ventilated people; (v) the ways in which the creative artistic process can authentically capture the realities of living with ventilation; and across inquiry, as a co-produced project, we want to (vi) better understand what kinds of principles and practices of co-production need to be developed to enhance health-related research.

Such a range of questions demands a transdisciplinary and multi-methods approach, and we outline these here. In order to explore the ways in which creative processes can capture the realities of living on and/or with ventilation, in our *Arts Stream* we employ performance (theater-based) and contemporary art practice, led by two Artists-in-Residence (Hale and Atkinson) to the project, to animate and give form to breathing and respiration as elements of life and death that are invisible, formless and taken for granted. Our Artists-in-Residence are people with lived experiences of both ventilation, progressive physical impairment and/or neurodivergence. The arts have long been used to examine the significance of breath. According to Fahd (2019: 177) ‘...while breathing operates at the margins of perception, its symbolic possibilities are frequently visualized in photography, video and performance-based works’ (see also Tremblay, 2018). We propose that accessible creative processes will offer new social texts of respiratory health and illness which can be the very means through which ‘to draw attention to the unobserved role of the breath in everyday life’ (Fahd, 2019: 177). Furthermore, research-informed theater has become a powerful tool to share research and co-construct data in radical ways that ‘disrupt hegemony while

offering a platform for counter hegemonic narratives and doings to appear’ (Schott, 2021: 117). We label our arts-methods participants as collaborators in recognition that they are also key knowledge producers in the process; as such our Artist Collaborators (ventilated people) are being remunerated as artists and will co-lead curation, exhibition and performance.

In order to make space for disabled, chronically ill and ventilated people to speak with and back to respiratory physicians and health services, communicating the lived and embodied experiences of ventilated lives, our *Ethnographic Stream* applies collaborative and creative ethnographic approaches specifically to patient ventilation journeys as these are happening in real-time. Our approach will involve spending time in hospital (the Northern General in Sheffield) observing clinicians at work and discussing their practice in interviews to understand the respiratory culture within which patients negotiate their treatment and seek support. We will also spend time with patients over a period of around 6 months to understand how they experience their initial diagnosis and intervention, and how they adjust to living on and with ventilatory technologies in the longer-term. Thus we will specifically explore instituting, or beginning, ventilation as a health intervention; its relationship to issues of ‘patient compliance’; the temporal and negotiated understandings of quality of life and ventilated futures and the ‘activity spaces’ regarding ventilator use (Walker et al., 2020). During these 6 months with participants we anticipate that we will encounter significant others too - relatives, friends, personal assistants, neighbors, pets - whose perspectives might help us to further understand the relational dimensions of living with ventilation. We will use a variety of ethnographic approaches including interviews, observation, video diaries and creative scrapbooking to offer participants choice in how they would like us to ‘be’ with them over this time. Our aim will be to co-construct with participants an approach which allows us to ‘follow’ ventilatory and breathing technologies from respiratory clinics at the hospital to participants’ homes to explore clinicians’ and patients’ understandings, expectations and negotiations of ventilator practice over time. Taking radical inspiration from a new ‘patchwork’ approach to ethnographic research (Günel et al., 2020), in a later section of this article we consider what ‘gentle’ co-construction in ethnographic research might look like - acknowledging that the personal commitments, priorities and needs of researchers are also an important consideration in care-full (see Budworth, 2023; Lonkila, 2021) research design.

Our *Narrative Stream* is being led by our Co-researcher Co-operative, a group of experts-by-experience that are employing virtual narrative methods to capture participants’ stories of ventilation. Often non-academic co-researchers are included in inquiry only in tokenistic ways; for example, they may be routinely excluded from the parts of the research that are deemed the preserve of academics, such as analysis and publication (Liddiard et al., 2019). To counter this, narrative and Photovoice data collection and analyses throughout the project will be accessible, collaborative and co-led by the Community Researcher Co-operative, who are being paid, and formally employed by our institution, as researchers across the project. Beyond research design and data collection, community researchers will co-lead public engagement and dissemination across multiple contexts, and will co-author for publication (see Liddiard et al., 2022). We discuss the value of the Community Researcher Co-operative to innovative disability research methodologies later in this article.

Finally, to consider the ways in which ventilation can be a vehicle for new conversations about life, death, disability and health in an ongoing pandemic and as we look to post-pandemic futures, in the *Archival Stream* we are currently virtually exploring sources that relate to both respiratory health and illness and ventilation as medical intervention and treatment. Embodying the politics of rewriting histories from the perspectives of marginalized people, we are re-conceptualizing archives to understand respiratory health in new ways in the context of archival sociology (White, 2012; Benzecry et al., 2020). We aim to ‘radicalize traditional approaches’ (Brilmyer, 2018: 1) in order to shift power relations that are historically reproduced through archives.

Now we have outlined the shape of our research design, in the next section of this article we critically reflect upon our first year working as a team to *crip* inquiry. We understand *crip* to mean ‘the non-compliant, anti-assimilationist position that disability is a desirable part of the world’ (Hamraie and Fritsch, 2019: 2). For us, *crip* extends to the research process, which includes how we support and care for each other to manage our project as a team. In doing so, we discuss our imperatives to embed inclusive working practices, develop relationships, and design care-full (see Budworth, 2023; Lonkila, 2021) methodological approaches. Following this, we move on to reflect upon the meanings and implications of rest and self-care as routine aspects of our research process - also an act of *Crip*. In the final section, to ‘build on a growing tradition of sharing the challenging moments of qualitative research’ (Bowtell et al., 2013: 652), we explore our own recent experiences of death within the research process and consider the meanings of grief, loss and legacy in both disability research and sociologies of health and illness. We conclude by calling for a more inclusive sociology.

Crippling inquiry: the story of our first year

In *Crippling Breath*, we are very purposefully engaging in slow scholarship (Mountz et al., 2015) to counter forms of ableism experienced by disabled researchers (and others) within the academy, to create an environment in which disability is desired and vital. We define ableism as ‘an ideology that privileges able-bodiedness and -mindedness and a preferential citizen as self-sufficient, autonomous, independent and entrepreneurial’ (Goodley et al., 2025: 121). To desire disability is underpinned by our understanding of *crip*, which is also informed by McRuer (2006: 35), with *crip* being that which ‘questions or takes a sledgehammer to that which has been concretised’. Our project title - *Crippling Breath* - demarcates our desire to unsettle, to contest and challenge normalcy around breath and breathing. We are also conscious of doing this work as a team made up of disabled, ventilated, chronically ill and ally researchers. Liddiard and Lawthom (in press: np) state that ‘critical to the way in which disabled women (and others) theorize disability in the world inherently relates to the conditions of an ableist academy’. As Jain (2023: 30) maintains, ‘the university is deeply rooted in ableist practices’. As Goodley et al. (2025: 121) explain: ‘disabled students and staff experience exclusionary admissions and recruitment, poor career pipelines and in/formal support, under-employment and precarity’. Brown and Leigh’s (2020) excellent edited collection of writings has for the first time emphasized the ways in which disabled and chronically ill

academics and researchers are now more cognisant of the ableist environments in which we work and the ways in which certain types of bodies and minds are both unexpected and unwelcome in the academy (see also Brown and Leigh, 2018). Aptly, ‘hiding, keeping up, disclosing, pushing yourself, coping, passing and masking are all practices that require emotional and other forms of labor for disabled and chronically ill people, both inside and outside of the academy’ (Liddiard and Lawthom, in press: np). Wilkinson and Wilkinson’s (2023: 4) powerful writing articulates the ways in which sick, disabled and ill bodies and people have to labor to ‘perform (un)spoiled academic identities’.

One of our project responses to such academic ableism, then, is slow scholarship, which ‘questions the ever-increasing demands of academic life, placing them broadly within wider tendencies toward neoliberal university governance’ (Mountz et al., 2015, p. 1238). As some of us have said elsewhere, it ‘...involves resistance, engaging slowly with the object of study, engaging with others and improving the quality of academic practices such as writing’ (Liddiard and Lawthom, in press: np). For us currently it involves playing with and pushing at the normative temporalities of the research process; often in ways that better fits a diversity of identities, embodiments and experiences. But it also relates to the ethics of how we wish to work. In *Crippling Breath* it began at the stage of co-designing the project in preparation for the funding bid to the Wellcome Trust. Cognisant of the ways in which authentic forms of co-production with marginalized people and their communities demand an ethic of care, we wanted to enact a co-production process in our project that meant something to disabled, chronically ill and ventilated people. A process that centers relational labors and a *crip* and feminist ethic of care which involves ‘empathy, reflection, anticipation, affirmation and compassion’ (Katzman et al., 2020: 519). Important to us all was that we took our time, and never felt rushed; accounted for illness, vulnerability, ableism and care within the process; and understood co-production, first and foremost, as a deeply relational practice (see Liddiard et al., 2024). Importantly, to support this, we applied for and were successful in gaining seed funding to pay partners and collaborators to support the co-authoring of the project application for the funder (see Liddiard et al., 2024). To be more transparent here in our aim to support other researchers, our principal investigator accessed a Women Academics’ returning to work Program (WARP) at our institution. This fund is purposeful toward supporting women academics in their return to research following periods of parental leave. We recognize the privilege of access to such internal funding, and that part of this is from being in a research-intensive university in the UK context.

Together, we co-designed and advocated for a 5 year project (2024–2028). This allowed us a full first year to come together as a diverse core research team - we are clinicians, artists, academics and others with lived and embodied experience of disability, chronic illness, and neurodivergence. Such transdisciplinarity means careful work, to listen to and appreciate one others’ perspectives and enact access in considered ways. Furthermore, in year one, we recruited our research associates through an inclusive process layered with care. Elsewhere we have articulated what this involved: ‘removing ableist language from job descriptions and person specifications; flexible forms of interview; accessible inductions and onboarding; and flexible and remote working as routine’ (Liddiard et al., 2024: 13–14). We had feedback from interviewees (who did not get the posts) which said that they were grateful for a “fully humanized process” (personal

correspondence, 2024) that was inclusive, accessible and - despite the institutional and bureaucratic context of university recruitment (see Goodley et al., 2025) - *caring*.

Furthermore, we have spent our first year deeply exploring the contexts in which we want to collect data: disability arts cultures and contexts and visits to see and build relationships with our disability organization and arts partners; visits to hospitals and healthcare spaces to learn the cultures in which our clinical ethnography will take place; sitting in (virtual) archives exploring the histories of medical technologies; and collectively thinking through inclusive and creative approaches to how we wanted to recruit our community researchers. Key to our co-produced approach is our Community Researcher Cooperative - a team of community-based researchers - all of whom live on and with ventilatory technologies and respiratory illness, who are working across the project to embed lived and embodied knowledge into our theory-building and co-lead our inclusive approaches to inquiry (see Liddiard et al., 2023). In our first year we have recruited 13 diverse community researchers and employed everyone on university employment contracts. This in itself was a process - beginning with liaising with Human Resources (HR) and other university systems about flexible and small contracts (e.g., contracts of 2–3 h per week) as well as advocating for grade 7 pay (a UK postdoctoral pay level) for people who are from a range of educational and employment backgrounds. This took an extensive amount of labor and negotiation with HR and others to understand why community researchers were working on such small fractional contracts; we hit institutional barriers here in terms of what labor looks like in the academy, and who is expected to be doing it (see Goodley et al., 2025 for a discussion of university bureaucracy as it relates to research processes). Our advice for other researchers here is to persevere - changing standardized institutional understandings of 'contribution' and 'labor' takes: (i) lots of time; (ii) collaboration *with* university systems and processes (rather than working against them); and (iii) the support of our Professional Services colleagues whose work sits within these systems. A good example of the latter here is that the technology the university uses to do the required Right to Work checks in the UK for someone to be eligible for employment was not accessible to many of our community researchers. This took significant support from our School Operations Team, and the kindness of a key Professional Services colleague here, to support community researchers to do manual Right to Work checks in order to become formally employed in contracts. Another hurdle we faced - not in relation to the institution - was ensuring that community researchers' income from government benefits were not impacted by their work on the project. We had to very carefully - and individually - work with each community researcher who was a recipient of benefits ('welfare') to work out how to manage university pay and income in a context where certain governmental benefits only allow permitted work hour/pay limits.

Moving forward, we continued on and developed an accessible recruitment animation with British Sign Language and Easy Read applications (Glover, 2024)¹, followed by accessible online interviews, and a program of work which commenced in early 2025 (year two) that centers things like co-authoring a collaboration agreement,

learning about narrative research together, and undertaking a collaborative institutional ethical application process.

Taking our time with the recruitment of our community researchers has meant that they are beautifully diverse: aged from 18 to 60+ with varied experiences of ventilatory technologies, some with a tracheostomy, others who use forms of non-invasive ventilation (NIV), some for a few months, others for a lifetime. People with congenital and acquired respiratory illness and impairment; people with myriad life experiences - former and current NHS workers, charity trustees, activists and campaigners, artists, volunteers and advocates and more. All community researchers share lived experiences of ventilation as an intervention in their lives and have a passion for social research and learning about the experiences of others. These were our only eligibility criteria.

The space for community researchers to explore and co-create on the project is organic to the often-changing needs and skills of the team. The Co-operative encourages flexible working patterns and aims to dismantle neoliberal-able (see Goodley, 2014) needs for consistency and routine. Instead, the Co-operative facilitates a space that enables fluctuating work patterns around other commitments, periods of ill-health and simply harnessing windows of "good health" to 'live'. Practically this is implemented with online meetings being recorded and made available on shared workspaces, asynchronous working, and 10 weeks of community researcher training that can be completed over 6 months. The space in which experiences are shared, and ideas are generated, is not bound by specific means of contribution, such as written feedback, but instead open to input in ways most comfortable to the community researcher including one-to-one informal conversations, group messaging and short and discreet reflexive tasks. The Lead Community Researcher (Glover) and Research Associate (Kettle) work closely to weave and bring together ideas into a shared vision for the Co-operative. Importantly, we designed a specific project post around supporting community researchers (the Lead Community Researcher) through learning about the everyday labors in making conventional research processes accessible to those who have not had formal academic training in a former project (see Liddiard et al., 2022).

Similarly, in the Arts Stream, we are currently in the process of recruiting six disabled artist collaborators who will undertake paid research informed theater and contemporary arts residencies within the project. Led by our Research Associate (Joseph) in collaboration with our Artists-in-Residence, this again is careful and critical work that rightly takes *time*: What counts as an artist, and art? Who do we need or want to work with? What kinds of ventilatory experiences do we require here? What counts as ventilation? How can we develop asynchronous, virtual, and accessible ways of making art and theater together? Meetings are (often joyfully) spent discussing, imagining, and thinking. We have had to undertake multiple complicated institutional ethics applications to enable this work to move forward; and our recruitment processes are being carefully curated and 'translated' into accessible formats such as British Sign Language (BSL) and Easy Read. We have had to reflect on *how* we will recruit our six artist collaborators, and put a lot of thought into the politics and practicalities of *selection*; and most importantly, the ethical considerations to support those who are *not* selected for a residency.

Thus, rather than jumping into data collection or systematic literature reviews as often happens in the first year of a funded empirical research project, we have spent time together, learning and

¹ https://youtu.be/KhYFrL4Q_QY

exploring together, thinking critically about how we will collaborate and co-produce new knowledge together. Viney explores the “projectification” of academic research: ‘It interests me that projects attempt to resolve research aims, questions, collaborating organizations, methods, and outputs before beginning their work. In this sense they are an organizational form antithetical to discovery research’ (Viney, 2024: np). Moreover, ‘...In the economic life of the project human lives – contract workers, participants, ‘patients’ – are rendered as technical inputs and outputs, so the performance of projects can be measured, graded, and optimized’ (Viney, 2024: np). Thus while we have had plans for our first year (because our funder required these as a prerequisite for funding), these have had to be truly flexible, moveable and subject to change at any time. As we have said elsewhere, Crippling Breath seeks to ‘push the boundaries of what’s possible (or not) in the neoliberal academy to play with the temporalities of normative research processes which are typically fast-paced, metric and output-oriented, inaccessible to many (and thus exclusionary), and which are fixed to accelerated timelines and follow the temporal regimes of the neoliberal university’ (Liddiard et al., 2024: 11).

Rest, recuperation and care

This section of our article follows on from an initial piece of writing published last year in the online medical humanities journal, *Polyphony* (Atkinson et al., 2024). In this short piece, some members of the research team came together to ‘draw upon personal narratives and embodied experiences of respiratory failure and neurodivergence to think through crip time’ (Atkinson et al., 2024, np). Working with Kafer’s (2013: 27) understanding of crip time as ‘flex time not just expanded but exploded’ we explored the ways in which time is experienced in different contexts and by different people within the wider project team, to understand how our inquiry can meaningfully center disability experiences, caring and embodiment. We also follow White (2023: 5), who defines crip time as ‘...a flexibility and an expansion of time, both in response to bodily necessity and to societal barriers that make it so that more time may in fact be necessary’. It was through thinking what time is and means, as humans working across a transdisciplinary research project together, that we arrived at the importance of rest, recuperation and recovery time in a project about health and illness led by disabled, chronically ill and neurodivergent researchers. In short, our desire for rest, recuperation and recovery time in Crippling Breath is a necessity, and we are making space for it and want to feel safe as we do so. In just 1 year of our project, we have had multiple team members die, be hospitalized, undergo emergency surgery, routinely be ‘off sick’ and need time away from the project (for themselves and those they care for), and we have had COVID-19, chest infections, pneumonia and influenza multiple times. As we have reflected previously, ‘living with forms of respiratory impairment and/or using ventilation can mean dealing with fatigue, breathlessness, limited energy (particularly over longer periods of time), and a sensitivity to minor illness, whereby something as simple as catching a cold can mean weeks of struggle and recovery’ (Atkinson et al., 2024: np). Thus, we are a project of vulnerable bodies (our own and others whom we care for). On the project start date, our Principal Investigator was sitting in an acute respiratory ward in hospital just focusing on trying to keep breathing - the irony was palpable - but this is what

Crippling Breath seeks to be: inquiry that centers lived and embodied experiences of respiratory illness, often in the rawest of ways. This can have very real material realities for our ways of working (Atkinson et al., 2024: np):

‘Project processes can and do get slowed down by prioritising flexibility around hospital appointments, taking time off sick, waiting for antibiotics and other medications to kick in, and managing sudden hospitalisations and surgeries. Actively making space for the team to rest, recuperate and recover takes on a new meaning as we build in contingencies, use organisational technologies to share and document our work so someone else can jump in when needed, and resist the work-intensive temporalities of academia.’

As we enter year two of our project, then, we are working on ways of co-developing a research environment and project culture that gives foundation to easier conversations about asking for ‘time away’ - in a way that does not ignite our own internalized ableism. Similar to internalized oppression, which ‘results in group members loathing themselves, disliking others in their group, and blaming themselves for the oppression’ (Rosenwasser, 2000: 1), internalized ableism operates as a form of psycho-emotional disablism. Psycho-emotional disablism is defined by Thomas (1999: 60) as ‘the socially engendered undermining of emotional well-being’. As Reeve (2004: 84, 2008) contends, for disabled people and others, it operates ‘at both the public and personal levels, affecting what people can do, as well as what they can be.’ As we intimated at the very beginning of this article, the university is a deeply ableist space - with ableism being ‘associated with the broader cultural logics of autonomy, self-sufficiency and independence’ (Goodley et al., 2018: 209). As disabled and ally researchers, then, to counter this, we are putting importance upon working in ways that encourage connection, care and interdependence as a team. In practice this means embracing flexibility, adaptability and radical care across the team, because we all bring various types of impairment, embodiment, chronic illness (see Piepzna-Samarasinha, 2018), as well as forms of caring responsibilities for intimate others. Explicit and unapologetic, or crip, recognition of this is both a political and practical matter. We are arranging our day-to-day work practices in ways which directly challenge narrow ableist notions of how we can be productive while harnessing the camaraderie which comes from experiencing ‘vulnerability’ as something we do not need to mask, ‘power through’ or feel ashamed about.

It is possible to center rest, recuperation and care within research design too, which is something we have taken our time to consider when setting up the ethnographic stream of Crippling Breath. Ethnography as it is traditionally (anthropologically) understood conjures up an image of the lone (often male, nearly always able bodied) researcher who is completely immersed in a distant, unfamiliar place for months, maybe even years, at a time. While there have been many challenges to this outdated, colonialist vision of ethnography (Uddin, 2011), oftentimes scholars assert the importance of doing ‘ethnography at home’ (Anderson, 2021) or they argue that contemporary social contexts require something different from ethnographers (e.g., online ethnography). While we completely agree with these arguments, the notion that ethnographic researchers *themselves* might need things that shape the kind of ethnography and knowledge production that is possible, necessitates rather more

radical thinking. In our work we have been influenced by a rallying call for ‘patchwork ethnography’; ‘a new methodological and theoretical approach’ which not only advocates for spatial and temporal reconfigurations of what it means to be ‘in the field’ but which also calls out the ableism and depoliticisation of researcher positionality that underpins traditional ideas about ethnography (Günel et al., 2020: np). A patchwork approach values the entwining personal and professional aspects of researchers’ lives and the possibilities this generates for ‘innovating methods and epistemologies to contend with intimate, personal, political, or material concerns’ (Günel et al., 2020: np). Put simply, the personal, relational and embodied needs of researchers and those they care for are important considerations in planning the logistics of how ethnographic research gets done. But more than this, these considerations make for productive, ‘kinder and gentler ways to do research’ (2020:np). As the authors write (Günel et al., 2020: np):

‘Rather than see the multiple commitments of researchers as constraints, we will reflect on what forms of knowledge and methodologies emerge in and through researchers’ life and work commitments’.

Leaving the field to collect a child from school, taking an hour away to attend a medical appointment with a partner, scheduling observations and interviews so there is time to get lunch, to go for a walk, to collect a prescription - by insisting these examples of everyday care are methodological issues, we are ‘cripping’ ethnographic design in ways which feel both deeply mundane and yet powerfully radical. In our ethnographic work which is being led by Ellis - a mother with a young child and caring responsibilities - we are actively planning fieldwork around regular days off and school holidays. We are also thinking about ways to avoid debilitating feelings of overwhelm which we know from personal experience can develop from feeling overstretched and internalizing ableist and neoliberal ideas about personal responsibility, professionalism and labor. Thus we argue that to configure the logistics of research by leading explicitly with compassion, and acknowledging the often complicated, messy, demanding lives of *both* participant and researcher is an important way to center inclusivity, recuperation and care in any sociological research design. As we shall explore in the next section on loss, navigating the fragility and unpredictability ever present in disability research (Budworth, 2023) makes this especially important.

Disability and death: accounting for loss in the research process

“We’ve got to start talking about death and dying. We need to reclaim the language. We need to narrate dying. It’s time.” (Watts, 2018)

The words above were written by a former colleague, Lucy Watts MBE, who has since died. Lucy worked with some of us as a co-researcher in a former project (see Liddiard et al., 2023 for the full story of Lucy’s contributions), and much of her work was rooted in promoting the need for and improving end of life planning and palliative care for young people (Watts, 2021). Her words here echo our desire to think carefully and mindfully about death in our project.

Just days after Crippling Breath began, our key collaborator Sally Whitney-Mitchell - a brilliant researcher who co-designed much of our co-production approach - lost her life at just 36. Sally was a researcher who enacted an ethic of care like never before. A researcher without any formal training, someone who fell in love with inquiry and writing (Whitney et al., 2019; see also Evans and Whitney-Mitchell, 2023) in her role as a lived experience co-researcher in a former funded project about disabled young people living with life limiting and life threatening impairments (Goodley et al., 2018), Sally was the lynchpin in our relational and affective approaches to co-production. Sally’s sudden death understandably took a lot of time to come to terms with for us as a team. Some of us had been working with Sally, across projects, for a number of years prior to her death. Since Sally’s death, we have also lost two of our community researchers. Their deaths occurred suddenly and very soon into their time working on the project. Beyond the sadness, a number of responsibilities came into view quickly: How do we inform our other community researchers, and what support could/should we offer when we do? How do we mark late community researchers’ contributions to the project? What, if anything, should we “say” as a project publicly? How can we send our love and best wishes to their partners, family members, and communities (see Bowtell et al., 2013)? Research that takes place in institutions (in this case, the university) also causes and demands a bureaucratic response (see Goodley et al., 2025). Things like reporting the death of a staff member (because our community researchers are on university contracts); negotiating with HR about the termination of contracts (‘I can confirm that no further action is needed for the post. We can pick this up again when you are ready to re-recruit’); and having difficult conversations around outstanding pay. Crip time is a useful lens here to understand the institution as needing to sequester death away quickly and neatly (see Samuels, 2017).

In this section, we focus on grief, loss, care and legacy in the research process in order to ‘build on a growing tradition of sharing the challenging moments of qualitative research’ (Bowtell et al., 2013: 652). We also again locate grief and death in the context of crip time; as Ellen Samuels says, ‘Crip time is grief time’ (Samuels, 2017; np). Our transparency - we hope - is productive toward supporting other researchers and projects. As a caveat, though, as people aligned to disability studies, we also recognize the risks in associating disability, vulnerability and death - or the personal tragedy model of disability (see Goodley et al., 2018) - in global ableist cultures where disabled people and their families are fighting for rights to live, thrive, be educated, employed and be included in their communities. From Britain, where we are writing, disabled people’s communities are actively fighting against the Terminally Ill Adults (End of Life) Bill 2024–25 which has recently had its second reading in the House of Commons, and we are also currently witnessing a new wave of austerity - which (again) centers on “reducing the costs” of disabled and chronically ill people - from our newly elected labor government. We understand deeply, then, that these ableist times promote and enact forms of neo-eugenic cultures that devalue the lives of disabled people (see Rembis, 2009; Shildrick, 2008).

Such a loss - the deaths of three team members in just 1 year of our project - has urged us to critically reflect upon death and bereavement. The very fact that we are exploring ventilation, respiratory illness, and disability as people with very particular clinical vulnerabilities means we, perhaps, have an inevitable proximity to

death that is worthy of attention. Markedly, there is a relative lack of focus about death in research in the literature, and more specifically, its impact on researchers (De Laine, 2000). As Borgstrom and Ellis (2020: 591) state, ‘...less attention has been paid to researcher vulnerability specifically and its methodological implications’ (see also Silverio et al., 2022). What happens when someone dies in the research process? How should we talk, think, and feel about death in a research project? What kinds of human, and humane, responses are needed? What forms of support do we have access to as researchers? These are all current questions we are working through in Crippling Breath. To us, these are important questions in the context of disability research, particularly that which aligns itself with the politics of crip (McRuer, 2006).

Our early experiences of loss in this project have brought into critical view the need for us all to think and talk explicitly about grief, loss and death in a research project (Lundquist and Husebo, 2020). Death is, and will be again, present in Crippling Breath, and we need the time and tools as a team to make sense of this and the emotionality it brings (Harrison, 2021; Samuels, 2017). It also requires us to think in flexible ways about who is ‘in’ the team - about the role of legacy within research (of Sally’s, and others’, indelible contributions). Crip time is further relevant to these questions of legacy because of the ways it challenges normative ideas around time, bodies, and lifespans, and specifically, the finality of death (see Ljuslinder et al., 2020). We must also ask important questions about how we talk and/or connect with one another about loss mindfully and with care for the individual (health) circumstances of different members of the team. We are, quite literally, working it out as we move through the project. For example, we have procured the services of a specialist grief practitioner to create a bespoke workshop for the research team. While not intended to ‘workshop our way out of’ dealing with death, we see the workshop as a start of a conversation, and space, in which we can sit with grief in the process. For our community researchers, who not only have lived experience that may mirror that of participants, but who have not done emotionally demanding or sensitive research (Dickson-Swift et al., 2009) before, we have co-developed a self-care protocol with and for them. This protocol exists as a live document which supports community researchers to identify and voice their distress in the process as researchers while also providing different kinds of routes to self-care. The protocol features detail on emotionally demanding research and acknowledging distress; the practicalities of how to support ourselves and others in the team and developing a self-care plan; how to set boundaries as a novice researcher; information about community researcher debriefs we want to offer community researchers after every narrative interview with a participant; and how to take a break from the project if needed, with an “I need to take a break” email template for community researchers to use to make having some time away easier. Our Lead Community Researcher also practices regular “check-ins,” and research workshops with and for community researchers in this first phase of the project seek to attend to emotion, vulnerability and reflexivity - ‘an explicit self-analysis of one’s own role in research’ (Borgstrom and Ellis, 2020: 592) - as a central part of our narrative inquiry. Moreover our community researchers are keen to co-develop a further protocol as to how we respond as a team of researchers - if and/or when - a participant dies between their participation in the project and the publication of findings. Key questions here might center on the ethics of re-telling late participants’ stories; the emotional

work of analyzing data from people we know have died; and again how to recognize and memorialize the deaths of participants. Our participants may die ‘early’, or young; or before those with expected, *normal* lifespans - what Samuels (2017: np) calls ‘the sheltered space of normative time’. As Samuels’s (2017: np) echoes, ‘Crip time is time travel. Disability and illness have the power to extract us from linear, progressive time with its normative life stages and cast us into a wormhole of backward and forward acceleration, jerky stops and starts, tedious intervals and abrupt endings’. Therefore, we are conscious to work against normative trends in the social sciences whereby, for many reasons, particularly for ethics committees, ‘often researchers are expected to conceal, deny, or demonstrate how they will minimize their [own] vulnerability’ (Borgstrom and Ellis, 2020: 591). One of our researchers (Ellis), who has researched the everyday aspects of illness, death, dying and bereavement in previous projects (see Reed et al., 2023; Borgstrom and Ellis, 2017; Ellis, 2013), has challenged us not to see grief and loss as inevitably harmful, but that in our future practice we need to find comfort in ‘sitting with the sadness’.

To again draw in crip time - ‘the non-linear, unpredictable, ever-changing, or multiply enfolded temporalities of being disabled’ (Chazan, 2023: 1) - thus far we have experienced the death of team members as *rupture*. Processes stopped or slowed, and had to be redesigned; talking about loss took precedence over process; sadness halted the ability to theorize; and legacy - making links between late team members’ past contributions and the future of the project - has come to the fore (see Samuels, 2017 for an exploration of the ‘less appealing aspects of crip time’, 2017: np). Thus, we want to argue here that these early experiences show that research is far more than an empirically-driven, increasingly metricised, bureaucratic exercise. *Feeling* our way through challenging experiences such as loss offers painful but potentially productive opportunities to enact crip politics as research practice - to find spaces, temporalities and ways of working that center intimacy, connection and care. In doing so we will challenge normative ideas about how research should ‘feel’, where, when and how it should happen and who it can involve.

Drawing some conclusions

In this article we have essentially storied the first year of our project, Crippling Breath: Toward a New Cultural Politics of Respiration, a 5 year transdisciplinary program of research funded by the Wellcome Trust. In doing so, we have drawn back the curtains on our processes as a diverse team, and discussed some common key challenges in disability research methodologies such as negotiating accessibility; challenging ableist and institutional notions of productivity; and co-creating inclusive methodological design. Our understanding of crip as ‘the non-compliant, anti-assimilationist position that disability is a desirable part of the world’ (Hamraie and Fritsch, 2019: 2) has anchored us to thinking critically about (normative) research processes; how we support and care for each other to manage our project as a team; the ways in which we embed inclusive working practices across the project; how we develop relationships both inside and outside of the research team; and design care-full (see Lonkila, 2021) methodological approaches like patchwork ethnography (Günel et al., 2020). We have also reflected upon the meanings and implications of rest and self-care as routine

aspects of our research process - for us, an integral act of crippling ways of being and doing in the project - and explored our own recent experiences of death within the project. We have shared the importance of embracing flexibility, adaptability and radical care as routine across our team, because we all bring various types of impairment, embodiment, chronic illness (see [Piepzna-Samarasinha, 2018](#)), and caring responsibilities. In telling our story, then, we hope our (often messy) experiences can inform and support other researchers to 'build on a growing tradition of sharing the challenging moments of qualitative research' ([Bowtell et al., 2013: 652](#)). We suggest this transparency may be a key way to develop radical and crip cultures of co-produced and innovative disability research methodologies and can support a more inclusive sociology.

Data availability statement

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

Author contributions

JE: Conceptualisation, Writing – original draft, Writing – review & editing. LA: Conceptualisation, Funding acquisition, Writing – review & editing. SG: Conceptualisation, Writing – review & editing. JK: Conceptualisation, Writing – review & editing. GJ: Conceptualisation, Writing – review & editing. JH: Conceptualisation, Funding acquisition, Writing – review & editing. AJ: Conceptualisation, Writing – review & editing. MC: Conceptualisation, Writing – review & editing. LB: Conceptualisation, Writing – review & editing. RB: Conceptualisation, Writing – review & editing. CO'K: Conceptualisation, Writing – review & editing. JN: Conceptualisation, Writing – review & editing. HA: Conceptualisation, Writing – review & editing. CT: Conceptualisation, Writing – review & editing. SW: Conceptualisation, Writing – review & editing. CC: Conceptualisation, Writing – review & editing. BG: Conceptualisation, Funding acquisition, Writing – review & editing. KW: Conceptualisation, Funding acquisition, Writing – review & editing. RL: Conceptualisation, Funding acquisition, Writing – review & editing. KL: Conceptualisation, Funding acquisition, Writing – original draft, Writing – review & editing.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Gnosis and counterstories: decolonial disability reflections on delinking as a transgressive social methodology

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This essay articulates an innovative counterstory-based methodology of decolonial delinking which disrupts the very epistemic foundations of sociological disciplinary boundaries and ways of thinking about the production and distribution of knowledges. As non-white co-authors, we have opted to follow to adopt an expansive conception of decolonial/border-thinking gnosis and delinking as a way to embrace all knowledges, particularly those which do not conform to disciplinary modes of exposition and rationalist systematicity within the epistemic conceptions of knowledge. Using two disabled counterstories as gnosis illustrations, our essay shows how their enactment transgresses established norms for addressing and engaging with traditional, discipline-bound epistemological concerns. As such, we aim to open theoretical and methodological avenues for decolonial and non-Eurocentric spheres of imagination. More specifically, since the worlds of mathematics and mathematics education are so dominated by rationalist and neurotypical epistemologies grounded on the Cartesian duality of matter vs. ideas, both of our illustrative counterstories will deal with aspects that disrupt such epistemological paradigms through intersectional cripistemologies.

KEYWORDS

counterstories, disability, epistemology, mathematics education, decolonization

This essay articulates an innovative counterstory-based methodology of decolonial delinking which disrupts the very epistemic foundations of sociological disciplinary boundaries¹ and ways of thinking about the production and distribution of knowledges. Former American Sociological Association President Aldon Morris (2015) has already questioned the way racialized conceptions of modernity during the era of sociology's birth ended up marginalizing the scholarly status of non-white classical sociologists such as W. E. B. Du Bois, the founder of the first sociological school in the United States. As non-white co-authors Alexis identifies as Latinx and disabled; Paulo identifies as Chinese-American and disability advocate and caretaker. As such, we have opted to follow Walter Mignolo's (2000, 2007, 2021) radical suggestion to adopt an expansive conception of

1 Although it has been demonstrated that disciplinary boundaries in sociology and other social sciences are not static (e.g., Abbott and Celarent, 2017), our concern here pertains the Eurocentric nature of the epistemological basis of sociology. By this we mean the Eurocentric knowledge legacy of classic sociological thinkers such as Comte, Marx, Webber, and Durkheim, whose westernized evolutionary rationalism does not leave room for decolonial gnosis-based approaches such as those proposed in the present essay.

decolonial/border-thinking gnosis and delinking² as a way to embrace all knowledges, particularly those which do not conform to disciplinary modes of exposition and rationalist systematicity within the epistemic conceptions of knowledge.

As Mignolo (2000) explains in the introduction to his volume on border-thinking, both gnosis and episteme are used to translate the word knowledge from the Greek. However, only the former captures non-systematic modalities of knowledge, encompassing all forms of wisdom seeking processes and activities. Thus, gnosis enables us to tap into nomad and non-colonized knowledges in line with the broad non-rationalist thinking space that Deleuze and Guattari (1987) encompass under the non-hierarchical analytical term nomadology. Within epistemic conceptions of existing sociological methodologies, the emphasis is placed on formal disciplinary systematicity in line with Eurocentric modernity principles. Not surprisingly, therefore, classical sociology only recognizes European “fathers” of the discipline, e.g., Marx, Weber, Durkheim and so forth. This in turn excludes multiple forms of non-rational and para-rational wisdom seeking mechanisms located within the gnosis decolonial and border-thinking spaces that Mignolo and other Latin American philosophers call radical exteriority (Vallega, 2014). Worst still, this Eurocentric epistemic tendency deliberately suppresses critical examinations of what Peruvian sociologist Aníbal Quijano (1991, 2000, 2007) characterizes as the intrinsic structural and ideological interdependence between modernity, rationality and coloniality.³ Being a sociologist by training, Quijano himself exemplifies the enactment of gnosis vs. epistemology by not circumscribing his work to the disciplinary confines of sociology. Quijano radically engages with various emancipatory knowledges and currents of wisdom, what has evolved into the dynamic sub-fields of decolonial and anti-colonial thought (Mignolo, 2021, preface).⁴ Mignolo thus

favors the philosophical term gnoseology⁵ which encompasses the study of all knowledges, and which was in use during scholasticism, that is prior to modernity.

Using two disabled LatDisCrit and pan-Asian DisCrit⁶ counterstories (Padilla, 2021) as gnosis illustrations, our essay shows how their enactment transgresses established norms for addressing and engaging with traditional, discipline-bound epistemological concerns. As such, we aim to open theoretical and methodological avenues for decolonial and non-Eurocentric spheres of imagination. More specifically, since the worlds of mathematics and mathematics education are so dominated by rationalist and neurotypical epistemologies grounded on the Cartesian duality of matter vs. ideas, both of our illustrative counterstories will deal with aspects that disrupt such epistemological paradigms through intersectional cripistemologies (Johnson and McRuer, 2014; Sandahl, 2003). These intersectional cripistemologies are unique insofar as they lean instead toward the enactment of decolonial gnosis. In so doing, we open delinking spaces of alternative anti-colonial imaginaries; thus, we pursue decolonial disability justice and anti-supremacist paradigms that expand social movement and public sociology’s horizons. Moreover, we examine the impact that these explorations have in advancing equity concerns in mathematics and mathematics education via the transgression of their Eurocentric, colonial and neo-colonial foundations (Andrade-Molina and Valero, 2015, 2017). In the following section, we start by explaining the practical gnosis meaning of delinking in relation to dewesternization and decolonial processes which, while being parallel and aimed at disrupting colonizing and westernizing knowledge, power, ways of being and value systems, are not identical in their scope and agentic implications. Next, we explore the epistemological and gnosis meaning of counterstories as counternarrative

2 We expand below the conceptual and methodological scope of delinking. For now, let us define it as the intentional movement away from discipline-bound knowledges, especially modalities of knowledge that epitomize rationalist and dualist ontology paradigms such as those of Descartes, Kant, and the bulk of European philosophers foundational to modernity as a colonizing and Eurocentric knowledge totality (see, Allen and Mendieta, 2021, Introduction).

3 Like Quijano, we conceptualize coloniality as qualitatively different to colonialism, which operates at the level of extractive macro-territorial relations involving a colonizing superpower, typically a nation state. As explained in the following section, the broad relational contours of coloniality stem from colonial matrices of power (CMP) whereby coloniality/modernity/destitution get intrinsically aligned through dynamics such as those of racialized, gendered, and we would add ableist modalities of capitalism (Quijano, 2007). In this regard, our position differs from conflation-based conceptualizations of decoloniality such as that of Leonardo et al. (2023) who seem to minimize the conceptual boundaries between decoloniality, postcoloniality, and anti-coloniality, especially since they conflate colonialism and coloniality in conjunction to how they operate within educational contexts. For us, the distinctive gnosis-based kind of delinking we are espousing can only be possible in the context of decoloniality, not so much in terms of both postcolonial and anti-colonial theorizing and practice, since their ethos is tied to particular types of discipline-based epistemology.

4 Anti-colonial thought involves both decolonial and postcolonial theorizing and practice. It also involves early decolonizing efforts aimed specifically at dismantling colonialism as Mignolo (2021, p. 17 and following) designates the specificity of this decolonizing descriptor with respect to decoloniality and decolonial delinking.

5 Also spelled as gnoseology and gnostology; yet never to be confused with nosology, the term reserved in psychiatry for the study and classification of mental disorders.

6 Several of Author’s works expand on LatDisCrit’s conceptual scope and applicability. This is the first time we employ the term Pan-Asian DisCrit. The DisCrit sub-field was initiated by Annamma et al. (2013) to argue for the intrinsic interlocking oppression interplay between race and disability as hierarchical matrices of othering. LatDisCrit merged ideas from LatCrit theory (which had originated as part of the critical legal movement of the 1970s with an emphasis on Latinx racialization and anti-discrimination concerns, see, Valdes and Bender, 2022) and DisCrit. In the case of pan-Asian DisCrit we are operating under a similar rationale, merging pan-Asian postcolonial thought with DisCrit (see, e.g., Chen, 2018; Chen et al., 2023; Coráñez Bolton, 2023). In so doing, we ground this merging process on the experiential and embodied dynamicity of firsthand counterstories whose reflexive space gives concrete metatheoretical power to crip pan-Asian alternative knowledge exploration and emancipatory learning (for an extensive treatment of emancipatory learning, see, Padilla, 2018, especially ch. 1).

social imagination tools, introducing and developing our two illustrative counterstories. Our essay concludes by exploring the emancipatory possibilities of gnosis and delinking in the realm of decolonial public sociology. We give preeminence to intersectional cripistemology spaces as the tip of the iceberg in an era marked by recalcitrant moves away from inclusive equity and cognitive respect to different ways of knowing, being and becoming.

From gnosis to delinking to decoloniality enactments

In this section, we address the nexus between gnosis, delinking and decoloniality. In addition to what we said in footnote 2 about delinking as a movement away from discipline-bound epistemological systematicity, it is important to establish several key dimensions associated with delinking as an innovative notion tied to decolonial cross-coalitional movement building as we use it in this essay. First, we stress that the gnosis-driven movement toward delinking is not merely or even mainly concerned with what Mignolo (2021) calls dewesternization. Mignolo points out emphatically that the process of dewesternization is one of the parallel dynamic historical trends that have resulted from the implosion of westernization's end of era which covered roughly from 1500 to 2000. Being the first era truly global in nature (Quijano and Wallerstein, 1992; Wallerstein, 1974), the westernization era was characterized by "political and economic unilaterality, and epistemic and aesthetic universality" (Mignolo, 2021, p. x). As a result of its implosive demise, cognitive and sociopolitical changes which before were regarded as unlikely, are becoming not only possible but tangible under new global realignments. "The pandemic only accelerated a process that is irreversible and provided more evidence that the long-lasting consequences of coloniality are no longer hidden under the rhetoric of modernity, development, progress, growth, 'more is better,' and 'bigger is virtuous'" (Mignolo, 2021). Secondly, in terms of our unique delinking emphasis, unlike the gnosis-driven power that results from conceptualizing delinking as border thinking spaces of decoloniality in action, the trajectory toward dewesternization has also been unilateral and strategically imposed by non-western forces driven by nation state agendas. Despite establishing the end of westernization as an era around the year 2000, Mignolo also recognizes that dewesternization had already been strategically promoted, especially in the last seven decades or so through state action which initially came about during the anti-colonial movements that proliferated in Africa and some Caribbean nations between the 1950s and the 1970s, but now it operates primarily through the China, Iran, Russia axis (Mignolo, 2021, p. 17 and following). The core decolonizing event in Mignolo's chronology is the Bandung Conference hosted by Indonesia in 1955. We do not have space to analyze in depth the dynamics this conference unleashed, especially regarding antiracist and non-aligned geopolitical movements (see, Mignolo, 2021, ch. 9). However, the conference represents a crucial geopolitical differentiating component to understand our third point when it comes to the unique kind of delinking we are underscoring, which is that decolonization and decoloniality are fundamentally different in terms of inter-state relations. Decolonization is about

the undoing of various modalities of colonialism which operate through inter-state relations. Decoloniality is much broader; it tackles the analysis and dismantling of the colonial matrix of power (CMP).⁷ Mignolo adds that CMP's operational elements have undergone three crucial processes that are by no means linear, often coexisting in complex ways since the year 1500: constitution, destitution and restitution. Coloniality and westernization were responsible for the first two of these processes. Yet, when it comes to restitution, both decoloniality and dewesternization are at work in parallel through very different mechanisms. Technically, therefore, both of them involve some form of delinking. Nonetheless, as we explain below, the operationalization of decolonial delinking as a distinctive sphere gets enacted within political society. In other words, it is reserved to dynamics that take place outside state spheres. This makes decolonial delinking particularly capacious for propelling border-thinking spaces through gnosis. In turn, its reconstitution is truly revolutionary, elevating all knowledges and giving peoplehood true intersectional and cross-coalitional agency. This gnosis-based kind of delinking thus operates in ways that radical solidarity becomes possible and genuinely transformational, activating so far marginalized wisdom seeking endeavors with actionable transgressive consequences (Padilla, 2018; Gaztambide-Fernández, 2012).

Our argument therefore in positioning delinking as intrinsic to gnosis-centered collective action, along with Mignolo's (2021) framing of decoloniality as an emancipatory ethos, is careful to stress that, ultimately, the decolonial project must not be a state sponsored process. Rather, it needs to be the product of agentic and collective enactments born within the dynamic sphere that Mignolo, following Chatterjee (2011) calls political society. It is interesting that Mignolo opts not to adopt the Marxian/Gramscian civil society terminology which has much more diffused usage in sociological circles. The reason stems from the desire to accentuate the political nature of decoloniality along with the kind of explicit sociopolitical orientation of the collective action involved in its brewing (see, e.g., Kumar Patnaik, 2025). To be sure, not all resistance collective action is decolonial; and as will be seen, the distinguishing features of decolonial collective action have to do with gnosis and delinking. In other words, as Fregoso Bailón et al. (2024) make clear, it is not enough to call something decolonial and still remain within the confines of western epistemological rationalism. To "overcome the present theoretical indifference, it is essential to detach ourselves from the colonial matrix—the oppressive logic that underpins Western society—and adopt a nomadic perspective that seamlessly transitions between diverse epistemological frameworks" (Fregoso Bailón et al., 2024, p. 2; see also, Paraskeva, 2022, p. 353 and following). Along with Fregoso et al., we are convinced that the nomadic and itinerant are intrinsic to gnosis-based knowledges and collective endeavors since they are not tied to disciplinary and rigidified rationalist boundaries. This is why Mignolo's conceptualization of border thinking adopts an itinerant stance. Border thinking deliberately adopts a suspicious attitude toward Eurocentric epistemologies

⁷ Figures 1.1, 1.2 and 1.3 in Mignolo (2021, ch. 1) represent graphically what is at stake conceptually and methodologically in the analysis of CMP, which Mignolo attributes to Quijano (2007).

and thus learns to delink from them. As Mignolo (2000, n.p.) himself puts it, border “thinking (or “border gnosis” ...) is a logical consequence of the colonial difference. It can be traced back to the initial moment of Spanish colonialism in the Andes and Mesoamerica.” That was the precise moment when Eurocentrism gave birth to its hierarchical ethos: when Europeans realized they could rule over previously unknown territories and racial categories. The Europeans started the complex process of self-shaping and “modernizing” via colonial extraction and redefining racialized civilizational walls under which disability also started emerging as a distinctively subaltern space, even for disabled Europeans. As such, the sense of cognitive dissonance of subaltern categories, disability included, traces back to what Wallerstein (1974) designates as the long sixteenth century, the period when world-system economic and sociopolitical structures and relations came into play. This dissonance to which Mignolo alludes stems from the hierarchical categorization of knowledges engendered by coloniality and modernity working in tandem. Their interlocking supremacist oppression mechanisms of exploitation and cultural/racializing/ableist marginalization work hand-in-hand with the placement of rationality above all forms of thinking and knowing. This happened despite many kinds of gnosis having existed and developed in parallel throughout the world without the global hindrance of the kind inaugurated by Eurocentrism (Alcoff, 2021), mathematics and mathematics education, of course, being among the disciplines where this tendency is most overwhelming (Andrade-Molina and Valero, 2015, 2017).

In terms of philosophy, for example, Mignolo points to Mudimbe's (1988) *The Invention of Africa: Gnosis, Philosophy and the Order of Knowledge* as one of the first volumes that made evident the need to abandon purely epistemological treatments of rationalist knowledge in order to embrace knowledges which do not conform to its reductionist parameters of thinking and understanding. However, it is paramount to look deeper at the sociopolitical dimensions of decoloniality as a freedom-seeking process. To this end, it is worth pausing briefly to understand better what Chatterjee (2011) means by political society as opposed to what European Marxian thinkers like Gramsci call civil society.

Chatterjee (2011) points out that there are classical concepts of political theory such as family, civil society, political society, and the state which nonetheless tend to be used most inconsistently. Hegel, for instance, elevated the family, civil society and state, but did not have a place for political society in his institutional modeling of sociopolitical arrangements (Hegel's choice is important because he influenced Marx and a good number of subsequent thinkers e.g., Gramsci). By political society Chatterjee means the domain of institutions that mediate between people and the state but which stand in parallel to civil society. Civil society is restricted to more or less autonomous voluntary associations (e.g., churches and non-profits) without explicit sociopolitical missions, very much in line with what Putnam (2000) examines as social capital networks of trust. In postcolonial societies, these civil society networks of trust are often coopted by the state through clientelist mechanisms. This, in turn, forces spheres of resistance and change making to reside within that alternative sphere of political society to which Chatterjee gives preeminence. It is also in this context of resistance and emancipatory spaces where it makes most sense to excavate the dynamic ethos of counterstories as incubation

domains of gnosis in action. This is what we foreground in the section that follows. Importantly, as an explicit delinking move, readers should note that the kind of embodied counterstory we have in mind and develop later in our essay, does not attempt to purify pedagogical mathematics practices to make them cosmetically liberatory insofar as they become somehow less ableist. Our gnosis-based aim is more radical. We want to tap into non-disciplined or undisciplined modalities of so-called minor mathematics (de Freitas and Sinclair, 2020). We do so on purpose to show that, especially within the domain of so-called profound and severe disabilities (and all intersectional disability spaces and experiences for that matter), there is powerful mathematical brilliance. In other words, we want to push against the famous Greek root of pedagogy as literally meaning the holding children by the hand to guide them somewhere (particularly since that somewhere is presumed not to be under the control of the child/learner). In terms of gnosis-based intersectional decoloniality, what is needed is exactly the opposite. We need to let go of their hands, bodies, dreams and souls so as to facilitate the free expression of these brilliances. Furthermore, we need to honor them as valuable and revolutionary funds of knowledge and anti-epistemological, that is, anti-disciplining modalities of delinking. We do so through the telling of their counterstories but there are probably multiple ways to achieve this aim and elevate such amazing myriad manifestations of subversive creativity.

Decolonial delinking through counterstories

We start this section by elevating the gnosis power of embodied, first person experiential counterstories whose ethos typically operates at the micro-level of analysis. Notwithstanding this micro-relational emphasis, embodied counterstories, especially in their intersectional anti-ableist contours are intrinsically political. They are not mere isolated vignettes. They do not give voice to a choir of depoliticized subjects. Herein thus resides their decolonial and situated emancipation gnosis-based spirit. Decolonial delinking through the power of counterstories, therefore, involves a deliberate process of anchoring collective action on gnosis as opposed to epistemology. Dimensions like poetic resistance, counterstory telling and non-rationalist wisdom seeking mechanisms acquire centerstage. The border-crossing work pursued by Chicana feminist thinkers such as Gloria Anzaldúa comes to mind here. Look for instance at how Anzaldúa (2015, n.p.) frames her gnosis-oriented knowledge pursuits:

Leaving home has cast you adrift in the liminal space between home and school, bereft of your former frame of reference. In class you feel you're on a rack, body prone across the equator between the diverse notions and nations that compose you. Remolinos (whirlwinds) sweep you off your feet, pulling you here and there. While home, family, and ethnic culture tug you back to the tribe, to the chicana indígena you were before, the anglo world sucks you toward an assimilated, homogenized, whitewashed identity. Each separate reality and its belief system vies with others to convert you to its worldview. Each exhorts you to turn your back on other interpretations,

other tribes. You face divisions within your cultures—divisions of class, gender, sexuality, nationality, and ethnicity. You face both entrenched institutions and the oppositional movements of working-class women, people of color, and queers. Pulled between opposing realities, you feel torn between “white” ways and Mexican ways, between Chicano nationalists and conservative Hispanics. Suspended between traditional values and feminist ideas, you don’t know whether to assimilate, separate, or isolate.

It is interesting that, although the word disability is never used by Anzaldúa, a lot of what she describes here seems in line with what mad activists (see, e.g., [Price, 2011](#)) would characterize as part of their everyday sense of non-rationalist reality embracing processes and their sense of pluriversal political ontology (to use Arturo [Escobar’s, 2020](#) terminology). Furthermore, there is an obvious intersectional, rather fragile quest for finding mechanisms of resistance. In many ways, our respective counterstories below mirror several of these characteristics. In particular, these counterstories’ focal agentic struggles operate within the broader confines of mathematics, a discipline that epitomizes the rationalist power of Eurocentric epistemologies as well as ableist, gendered and racialized ideologies of western knowledge supremacy ([Mikulan and Sinclair, 2024](#)).

Paulo and Kai’s counterstory: in search of gnosis as a catalyzing liberatory space

Profound is a word used by non-disabled folks (and unfortunately many disabled individuals as well) to describe a category of disability that warrants certain types of responses, interventions, practices, policies, etc. in US K-12 schools. It’s often coupled with the word severe. The category severe-profound disabilities signal an almost nullified educational expectation where so called life-skills take precedence over academic ones ([Jorgensen et al., 2010](#)). Simultaneously, it applies to a particular level of support that, although qualified as needed for those who are so labeled and thus determined to fall within this category, is also regarded as not fundamentally useful to push the learning limits of a space so mysterious that ends up in practice deemed as pedagogically pointless and devoid of false achievement hopes. Professionals such as educators and psychologists had determined that Kai (pseudonym) who is now 21 years-old and someone who I have advocated for, fell into the severe-profound disability category. This happened as his first encounter with the public education system in the US at the early age of three. As with Kai, those identified in the severe-profound category are most likely to be segregated from their non-disabled peers (i.e., taught in separate classrooms and/or schools) and engage in an extremely watered-down curriculum for the entirety of their K-12 schooling experience. What’s fascinating is that the word profound is also used in other, more valuable senses. It is used to describe the depth of knowledge and learning that one experiences over a long-course period. As a Chinese-American advocate and caretaker for and with persons with profound disability, mathematics education scholar,

brother, son, immigrant, and non-disabled person, I’d describe my experiences with advocating for Kai and his parents as a profound form of knowledge and emotional production and distribution that has evolved over the past 21 years. This evolution and complex sense of becoming has involved enriching, ongoing, and entangled experiences with them which have transformed my own sense of being and my own capacity for non-rationalist wisdom cultivation.

Early interventions

Kai was diagnosed with autism at the age of two. During that time I was just starting my doctoral studies in mathematics education. The psychologist who made the diagnosis suggested to Kai’s parents to “drop everything” and focus on intensive levels of early interventions to ensure Kai the best possible outcomes in terms of reducing the problems associated with autism. That is to say, these interventions aimed at fixing autism to make Kai function more normally. So addressing autism early was crucial to ensure a more normal human development. At that period in my life, I fully agreed with the prospects of having Kai become more normal. Like me and his parents Kai is an East-Asian appearing person. Relatively speaking, autism at the time was still relatively new and was framed in very tragic and scary ways. A team of white-female educators developed an Individualized Family Service Plan (IFSP) for Kai. The IFSP is a legally binding document that specifies which services and supports the state will provide for young children. IFSPs stipulate in-home services such as occupational, speech, and play therapy with Kai and his parents as participants. The focus of these therapies was not only to remediate areas where Kai lagged his typically developing peers but also to train parents to provide these therapies. These therapies were and continued to be underpinned by Western cultural norms (e.g., taking turns, individualistic, making eye contact).

Kai’s parents shared with me that they really dreaded these therapy sessions. They had a hard time focusing and would often find themselves dozing off. More concerning was that Kai would start crying once he associated the ring of the doorbell with the therapist’s arrival to conduct a session. The sessions focused on therapist modeling interventions strategies on Kai so that his parents could implement them regularly throughout Kai’s day. These interventions were guided by applied behavior analysis (ABA) techniques such that desired behaviors (e.g., making eye contact) could be shaped while undesired behaviors (e.g., stimming) would be extinguished or replaced with a more appropriate behavior. Scholars have critiqued ABA as a dehumanizing approach used to normalize autistic folks (e.g., [Broderick, 2009](#); [Roscigno, 2019](#); [Williams, 2018](#)). Kai did and continues to stim regularly. At the time, his parents and I considered his stimming a big problem as it interfered with his therapy. His parents demanded him to quiet his hands, to sit still, and make regular eye contact as a way to have him more focus on learning activities to meet certain able-bodied learning goals and Westernized norms. His parents noticed that Kai tried, but never to an acceptable level as his stimming needs would usually be too overwhelming. Of course, reframed as expressivity, these needs acquire such a different aura. This is an aura that when thinking of disciplinary rationalist spaces such as those

of mathematics reflect a powerful anti-disciplinary, gnosis-based delinking revolution whose very transgressiveness opens up the door to funds of knowledge as of yet unexplored in traditional, deficit-centered pedagogical spaces (de Freitas and Sinclair, 2014).

During this time, I did more self-learning on ABA and I became fascinated by some of the prominent research in this area. In particular, I read about the University of California, Los Angeles (UCLA) Young Autism Project and was amazed by the results the researchers were able to achieve with intense-levels of ABA therapy with young autistic children. This research showed that children who received these interventions were indistinguishable from normally developing children which I now realize showed clearly their ableist bias by centering on enacting normalcy ideology and practices. As his advocate, these were the results I all wanted for Kai, to be normal. It's paramount to realize that this desire for normalcy is an assimilationist stance that many immigrants to the US, such as Kai's parents and I, who strive to just fit in. We wanted Kai to have everything that we wanted in life, the so-called American dream, buying a house, having a family, and having a good paying job. ABA appeared to provide Kai and his parents with a key to that dream. What's wrong with that?

Rejecting systems of oppressions, unlearning hegemonic knowledges

Between those early years in Kai's life and now, Kai and I have evolved and continue to do so in profound and radical ways—an earthquake of knowledge development. Our on-going process involving co-becoming, struggling, studying, and the experiences navigating the oppressive environments that we co-inhabit has resulted in our current resistance stance, one that I describe as anti-ableist, antiracist, and anti-colonial (in this case meaning more than decolonial at the micro-level of resistance, see, e.g., Scribano, 2021).

As I developed my own critical consciousness since resuming my doctoral studies, I began to notice Kai's agency and unique gnosis-based expressivity as a disabled person of Chinese descent. I now realize that his agency unfolds through acts of resistance against a colonizing society not built for disabled folks (Ho, 2020) and their intersectionalities (Piepzna-Samarasinha, 2018). Thus, a critical theory, reflection, and praxis (Freire, 1970/2000) relationality occurred and continues to occur within and between Kai and me and beyond. Our daily interactions have shaped and keep being shaped by what we each bring. Kai brings his set of theories in the flesh (Moraga and Anzaldúa, 1981), one based on his lived experiences as an autistic and Chinese-American male who uses non-speaking modes of communication. I bring my experience as an academic who studies advancing intersectional disability justice in and through mathematics education. I also spent 10 years as a public school mathematics teacher in the US. In turn, my own experiential growth as educator and scholar has made me realize that the knowledge that develops from our interactions is profound in that it is a culmination of particular forms of relationalities, experiences, and theories that focus on and transcend mathematics education.

In particular, I've gained profound levels of understanding of disabilities and have applied this understanding to my personal and professional lives. For me, these two spheres of life are not

separate but are intimately entangled. For example, throughout Kai's K-12 schooling experiences, I was involved as a member of his Individualized Educational Program (IEP) meetings whereby my knowledge informed and was informed by those often contentious encounters. Coupled with my own set of experiences and expertise, I attempted to bring Kai's unique gnosis-based ways of knowing and doing mathematics from outside of schooling contexts to inform his IEP goals in mathematics—a form of knowing and doing that counters but also expands dominant forms of mathematics education or what de Freitas and Sinclair (2020) call “major mathematics.” I wanted these goals to depart from building on gnosis dimensions instead of relying on dominant epistemic ways of knowing and educating which, as should be evident to the reader, are charged with ableist, normalcy-imposing assumptions. For example, most educators ascribe to ideals that verbal and written forms of mathematics expressions are the only ways a student can demonstrate mathematics learning and competency. Here IEPs heavily reinforce these ideals with the requirement that goals need to be observable and measurable which taken at the surface level can be severely restrictive. Thus, I proposed more transgressive IEP mathematics goals (e.g., moving from only narrow skills-based goals to ones focused on communicating mathematical reasoning⁸) as well as the supports needed to meet these goals (e.g., teacher professional development and resources) that directly challenge these ideals while affirming more expansive ways of knowing and doing mathematics (e.g., delinking measurability and quantification). In doing so, I recognize this work as anti-ableist, antiracist, and anti-colonial in its delinking ethos. This work is also profound for many mathematics educators in recognizing a much broader realm of mathematics knowing and doing that exist in their classrooms. Thus, for both Kai and myself, the resistance work at stake is about de-centering dominant forms of mathematics education that have privileged and continue to elevate Eurocentric, able-bodied, and colonizer mathematics while profoundly enriching this relational field.

Alexis' counterstory: on the crafting and abandonment of improvisational gnosis spatiality of minor mathematics

In this second counterstory, we take up once more the theme of intersectional decoloniality through gnosis-based delinking. Yet in this case, the framing comes through the embodied experiences of a brown blind male working-class agent. As a disabled person residing in the global South, I was faced with a critical tension regarding my love for music, which in my case, meant an intimate engagement with what de Freitas and Sinclair (2020) encompass under the expression minor mathematics, those that “are often erased by state-sanctioned curricular images of mathematics” and “buried under ‘major’ settler mathematics” (p. 1). In the world of science education, it is relatively common to hear the expression citizen science (c.f., Herodotou et al., 2018). Nonetheless, minor mathematics goes further by underscoring gnosis-centered ways

⁸ See for example Tan et al. (2019) where an expansive conception of mathematical reasoning is adopted as a way to humanize disabilities within classroom relational contexts.

of thinking and doing mathematics completely outside of the discipline and especially out of classroom-bound ecologies of learning. I fit this profile since I never was what you could call a professional mathematics or mathematics education practitioner, as was clearly the case with Paulo. For me, that engagement came vicariously, especially as I studied musical theory and musical notation during my conservatory years, learning to master the flute in the 1980s. Those studies mimicked the oppositional tension between gnosis and episteme. By the time I went to the conservatory I had already mastered the recorder. However, in the case of the recorder, my engagement reflected a fluid, much less formal regime which in my home country was alluded to among musicians under the informal, almost disrespectful nomenclature of “guataca.” As a radical gnosis, rather undisciplined experience of learning and performing the embedded minor mathematics of music, guataca is a delinking term. It gets reserved for autodidactic, self-learning instances of musical enhancement and execution. In a way, guataca is also an exclusionary term since it alludes to musical instances where musical notations are completely absent and even irrelevant, making them anti-academic and anti-classical by definition (even if the improvisational performance involves classical pieces). My recorder and I were partners.

That partnership started almost accidentally the day I turned 9. That particular day in July there were several early childhood visitors to my boarding school for the blind. As usual, when visitors came, I as the poster boy was designated as the main interlocutor among all students. That had allowed me to interact with press professionals and other kinds of visitors numerous times under diverse circumstances. But that day, the topic of my birthday came up and I was asked by one of the teaching visitors what I wanted as a gift. It so happened that we had been talking about the recorder in my music class. Hence, I asked for a recorder.

It took me years to master the recorder, with the complicit torturous experience of my family members who endured the process not without legitimate complaints. The most important feature of that learning process was the sense of freedom it allowed me. It was embodied gnosis in action. It definitely felt emancipatory. Paradoxically, nonetheless, my critical engagement with pan-disability culture⁹ (Padilla and Tan, 2019) soon taught me that both conservatory and guataca music experiences were seen among my specific disability category as a stereotypical professional sphere of allowable mastery skills. In other words, excelling in music was a naturalized attribute granted by ableist supremacist and normalizing ideologues to the disabled as something to be expected from my specific anti-ableist everyday front line interactional vantage point. This in turn created an ethical dilemma: Should I behave in ways that would perpetuate such a stereotypical self-fulfilling prophecy? Should I instead break away from the chains of its irrevocable imprisonment?

Three years ago (Padilla, 2022), I published an essay that addressed indirectly some of these issues. One of my arguments in that rather philosophical piece of critical autoethnography was

that, apart from the proactive understanding and denunciation of the colonality of power, knowledge and being, as extensively carried out by Latin American and Caribbean thinkers (see, e.g., Maldonado-Torres, 2007; Wynter, 2003), one also needs to add a fourth category: the colonality of ethics or axiology. This involves addressing pan-disabled ethical dilemmas of the sort described above. This is not a minor dimension; it essentially entails giving up things one loves and that are part of one's identity for the sake of explicitly counteracting ableist stereotypes. In other words, for me to decide not giving it up would have involve a perfectly legitimate choice. However, it would also involve an inner struggle with one's own sense of radical exteriority (e.g., extreme othering), to use once more here Vallega's (2014) notion which he borrows from Levinas.

Looking at this epistemological struggle as a disabled scholar and activist, I now realize that my assessment of the situation at the time was probably too bound by epistemological considerations of what was demanded from me as an embodiment of disabled activism. From a gnosis standpoint, both music and positivist experiences of sociology were perfectly viable, even for a disabled person who was aspiring to an academic career in the social sciences. Adopting a much more flexible stance toward the rationalist disciplinarity of the social sciences would probably have helped as well. Perhaps many of my own anti-ableist tensions were a reflection of my colonized sense of consciousness. Such sense demanded some kind of linear externalized engagement against these stereotypical modalities of supremacist “permission” for pan-disabled people to engage in whatever activity they deem gratifying or part of their self-growth. My choice today would probably be different. Nonetheless, the damage has already been operationalized. Still, I am glad that my reflexive engagement now permits me to rescue this minor mathematics experience as a way to defend the expansive power of gnosis-based conceptions of knowledge with its consequential freedom enacting ethos as intrinsic to delinking in action.

Final reflections on gnosis-based embodied counterstories: revolutionizing the public in public sociology?

This essay has demonstrated the reductionist and colonizing nature of epistemological, discipline-bound and rationalist conceptions of knowledge. Particularly in relation to radical criptistemologies in action (c.f., Macioce, 2022), we would like to extrapolate several important considerations regarding the use of gnosis as a reference point for equity-based transformation in delinking practices. Doing so may help take so-called public scholarship in sociology and beyond to new and transgressional horizons. We invite the reader to keep in mind nonetheless that our recurrent focus on mathematics as a deficit-based discipline colonized by the supremacist ethos of Eurocentric ideologies of normalcy is liberatory not in the sense that we desire to rescue its disciplinary integrity. Quite on the contrary, our aim through these reflections is to foster an invitational dialogue about the need to transcend disciplinary walls. We do so by embracing marginalized delinking knowledges in their own terms and in their own rights to expand on what they have done so well for centuries: disrupt

⁹ By this expression, we mean unique culturally relevant funds of knowledge which derive from the collective engagement in anti-ableist struggles by disabled individuals across the full spectrum of multiple categories of disability, even in cases where these forms of disability remain invisible or have not yet been embraced as part of their inner sense of identity.

established epistemological canons and normalcy-imposing monolithic domination.

In terms of decolonial delinking, both of the counterstories explored in the second half of the essay show that intersectional disability emancipation in its gnosis-based modality is relational, not merely individualist or self-enhancing. Grounded as it is in the complex realms of political society at the conflating oppressiveness of coloniality, modernity and racialized capitalism (Quijano, 1991, 2007), its emancipatory awakenings do not need to wait for policies and state sponsored formalities to be promulgated. It starts manifesting in the everydayness of anti-oppressive modes of resistance that make up cognitive and structural struggles, showing once again that, as Tuck and Yang (2012) indicated over a decade ago, the decolonial contours of actionable decolonization are not part of a metaphor, a sort of discursive game. They are living enactments of resistance and transformation that tackle, as in Paulo and Kai's embodied counterstory, the contours of embodiment level modes of coloniality in action, or in Alexis' counterstory, the colonizing dimensions of so-called independent living for disabled folks as well as their "legitimate" learning pathways outside formal/rationalist dimensions of knowledge and performativity. Furthermore, the living manifestations of decolonial disability highlighted by both of our counterstories show the false dichotomy between what some thinkers call land-based vs. epistemology-based modes of decoloniality (Motala, 2025; Zembylas, 2025). By not staying at the territorial extraction level which colonialism emphasizes, decolonial disability makes clear that the complex interactions between exploitation, oppression and knowledge-based modes of epistemicide demand a sophisticated gnosis-centered analysis which helps expose and decode the destructive mechanisms of their coloniality matrices of power (CMP). Here is where public sociology comes in. In other words, because disability dimensions seem not to have territorial implications, a narrow focus on colonialism vs. coloniality is likely to miss the power, knowledge, being/becoming, and ethical relationality contours of its complexified modes of oppression and liberation. So far, this is why most decolonial sociology has essentially ignored disability and anti-ableism matters. Ultimately, our aim with the present paper is thus to promote decolonial delinking forms of situational emancipation which can be analytically approached in several ways.

First, by realizing that in its very definition, gnosis-based, embodied counterstories turn the table on matters of expertise. One can think of Kai's reversal of teaching canons concerning delinking modes of expressivity in mathematics. Kai's relational engagement with Paulo was at once natural and transgressional. It was natural as a familial curvilinear trajectory of love and learning. Yet it became transgressional as it provided Paulo mathematical and pedagogical knowledges he could not have accessed through traditional epistemological contexts of discipline-bound conceptions of mathematics and so-called special mathematics education. This relational illustration elevates a decolonial disability justice point that underlies every section in this essay: only intersectional pan-disabled folks have the power to authentically convey their experiences in a reflexive, critically grounded manner. This realization constitutes something intrinsically contrary to epistemology as we know it, particularly within rationalist disciplines such as mathematics and mathematics education. Secondly, because of this, by radically elevating gnosis-based practices in public scholarship and activism, one can at

last embody a genuine kind of marginalized scholarship and actionable decoloniality. This can be enacted within the sphere of political society, that is outside of both a political civil society and state-sponsored agendas. This in turn is at once an expression of activist research by and with pan-disabled groups as well as other intersectional actors. So far, public sociology, especially in terms of so-called inclusive equity, has been vulnerable to the enactment of expansive speaking engagements by pseudo disciplinary experts. Such experts relate to pan-disabled individuals as objects of their knowledge, not as agentic subjects who create and distribute cripistemological epiphanies as described in Paulo and Kai's counterstory. This kind of transgressive realignment of public scholarship must be carried out in terms delineated by disabled people's own experiential assessment of situations and relevant emancipatory responses (something which we are convinced is perfectly feasible and necessary for disabled groups covered by the profound and severe banner of alienation and non-agentic domination).

Our counterstories therefore reveal examples of how we can move toward liberatory mathematics education. Instead of looking for liberation within the epistemological chains imposed by disciplines, its enactment must come about through cross-coalitional cripistemologies in action. It must above all resist hegemonic knowledges with their rationalist reductionism. Our counterstories give texture to minor mathematics practices that disabled folks engage in their daily lives. Mathematics, contrary to common conception and especially in terms of how it materializes in schools, is not a rigid set of static knowledge to be ritualistically practiced. Rather, mathematics is a relational practice between and within humans and non-humans (as in Alexis' interactions with his recorder or as it is clearly manifested for blind individuals who share their lives with guide dogs. On this, see, e.g., Michalko, 1999, 2001). Such relational practice can be profoundly enhanced through these more diverse and minor ways of knowing and doing mathematics. That is to say in disrupting the very epistemic foundations of disciplinary boundaries and impositions, we create more emancipatory spaces from within and from without for genuine liberation grounded in the dignity of multiple knowledges, particularly those which have felt outside or have never been part of the canon blessed by dominant colonizing Eurocentric modes of epistemology.

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Rethinking digital and AI inclusion: participatory and intersectionality-informed methods for disability and migrant justice

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Everyday consumer technologies are increasingly integral to autonomy, mobility, and social participation among people with disabilities and migrants from culturally and linguistically diverse (CaLD) backgrounds. However, these technologies often remain inaccessible and exclusionary at the intersection of these identities. This study examined how CaLD migrants with disabilities engage with everyday consumer technologies using participatory and intersectionality-informed approaches. This article focuses on Stage Two of the Autonomy, Diversity & Disability: Everyday Practices of Technology project, funded by the Australian Research Council industry partnership grant (LP: 190900099), which involved individual interviews, creative workshops, guided discussions, post-workshop reflections, and the co-creation of AI-generated e-books. Drawing on three case studies, the analysis identified three key findings: (1) participants experienced a disproportionate burden in navigating digital accessibility and advocating for their needs; (2) generative AI perpetuated biases and misrepresentations of intersecting identities; and (3) participants actively used everyday consumer technologies to foster agency, learning, caregiving, and cultural connection. Through sustained participatory engagement, the researchers identified methodological parameters to inform future disability-inclusive, participatory, and intersectionality-informed research.

KEYWORDS

disability, migration, digital, inclusion, engagement, accessibility, AI, technology

1 Introduction

Everyday consumer technologies, such as smartphones, messaging apps, and GPS navigation, have become deeply embedded into everyday life, shaping how individuals connect, navigate, and access essential services across digital and physical spaces. For individuals with disabilities, these technologies support decision-making, mobility, and communication, which collectively foster greater autonomy (Al Zidjaly, 2015; Steel, 2019), demonstrating their transformative potential in everyday life and fostering empowered, independent living (Ellis, 2016; Goggin, 2017; Ellis and Kent, 2016, 2010). Similarly, for culturally and linguistically diverse (CaLD) migrants, such technologies play a critical role

in resettlement, social participation, and transnational connections (SSI, 2018; Caluya et al., 2018).

In Australia, CaLD migrants constitute one of the fastest-growing population groups, particularly in metropolitan and peri-urban regions such as Sydney and Melbourne, where established migrant communities provide critical social, economic, and cultural support (Australian Bureau of Statistics, 2021; SSI, 2018). Sydney, in particular, has seen an increase in concentrated ethnic communities, where everyday consumer technologies serve as a crucial link to public and private services, intra-community communication, and socio-economic participation (Pasquale, 2015; Caluya et al., 2018). However, despite these demographic shifts, Australia's digital infrastructures and mainstream everyday consumer technologies remain predominantly designed for an Anglo-centric user base, failing to adequately address the cultural, linguistic and accessibility needs of CaLD migrants.

This exclusionary nature is further compounded by algorithmic biases embedded in artificial intelligence (AI) systems, which are often trained on datasets that perpetuate linguistic and ableist biases (Pasquale, 2015; Noble, 2018). These biases situate everyday consumer technologies within socio-technical systems that reinforce existing power hierarchies rather than universally accessible tools they are intended to be (Heeks, 2022; Goggin, 2017). Of particular concern is the exclusion of CaLD migrants with disabilities—especially those who acquire disability before the age of 65. They remain one of the most under-served and under-resourced user groups in Australia (Soldatic et al., 2014; SSI, 2018) which further exacerbates their exclusion from essential digital and public services [Women With Disabilities Australia (WWDA), Harmony Alliance and National Ethnic Disability Alliance (NEDA), 2023].

While a growing body of research has examined disability and CaLD migration in relation to technology engagement (Al Zidjaly, 2015; Watermeyer and Goggin, 2019; Whitehead et al., 2023), these studies have largely examined disability and CaLD migration as distinct areas of inquiry, with limited attention given to their intersection (Swartz and Marchetti-Mercer, 2019). Recent pilot research conducted in Australia (Soldatic et al., 2020) further underscore these gaps, revealing that service providers and users alike report that everyday consumer technologies are inadequately adapted to the needs of CaLD migrants with disabilities, making them inaccessible, unaffordable, and stigmatizing. Users emphasized that technological developments aimed at improving access to digital and public services often addressed either their CaLD migrant identity or their disability but rarely considered the intersection of both. Consequently, individuals at this intersection face substantial accessibility and usability barriers, ultimately limiting the transformative potential of everyday consumer technologies (Parette and Scherer, 2004).

Addressing these structural limitations, an intersectional lens provides a critical framework for understanding how multiple intersecting systems of power shape the technology experiences of CaLD migrants with disabilities. First articulated by the Combahee River Collective (1977) and later formalized as a theoretical framework by Crenshaw (1991), intersectionality critiques single-axis approaches to oppression and emphasizes that overlapping systems of power interact to create distinct and compounded

forms of exclusion. This framework has since been widely adopted across disciplines, including disability studies, where scholars emphasized the necessity of examining multiple dimensions of systemic oppression to understand the lived realities of individuals with disabilities (Wolbring and Nasir, 2024). However, disability-digital research remains largely situated within a Western, Anglo-centric paradigm that overlooks the intersections of disability and CaLD identity, thereby perpetuating the exclusion of CaLD migrants with disabilities from digital infrastructures and mainstream technologies.

In response to these challenges, the Autonomy, Diversity & Disability: Everyday Practices of Technology (ADDEPT) project, funded by the Australian Research Council industry partnership grant (LP: 190900099), was established to explore the intersections of disability and CaLD migrant identity in relation to technology engagement through an intersectional lens. Conducted between 2020 and 2023, the project explored how CaLD migrants with disabilities navigate, engage with, and adapt everyday consumer technologies in their daily lives. Utilizing participatory, co-creation approach, the project engaged CaLD migrants with disabilities, community leaders, and service providers to critically examine accessibility barriers, digital participation, and systemic exclusion that shape their technological interactions. The ADDEPT project was structured into five phases (Table 1), each designed to investigate different aspects of technology engagement among CaLD migrants with disabilities.

Stage one (Phases 1, 2, and 5) focused on identifying digital barriers, gathering empirical insights, and translating findings into policy and practice recommendations through participatory workshops, focus groups, and interviews. Stage Two (Phases 3 & 4) adopted an innovative and experiential approach by integrating interactive workshops, self-reflective storytelling, and notably, generative AI-assisted content creation. This latter stage was significant for its application of generative AI systems in creating e-books that visually illustrate participants' engagement with everyday consumer technologies. By enabling participants to co-create AI-generated narratives, Stage Two not only documented their lived experiences but also revealed the algorithmic biases embedded in AI-generated media representations. This methodology paper focuses specifically on Stage Two, detailing the participatory, and intersectionality-informed research approaches used in co-creating AI-generated e-books. The subsequent sections outline the theoretical framework, participant, data collection methods, and case study findings. Additionally, ethical considerations and key methodological adaptations made in response to the COVID-19 pandemic are discussed. This ADDEPT project received ethics approval from Western Sydney University (H14057).

2 Methodology

This section details the research methods developed, applied and adapted to accommodate participants' needs while remaining flexible in response to evolving research constraints, particularly within the context of the COVID-19 pandemic. While these constraints required adjustments to anticipated methods and

TABLE 1 ADDEPT project outline.

	Stage one	Stage two
Phases	1, 2, and 5	3 and 4
Data collection methods	Focus groups, interviews, and one-day forum	Interactive workshops, self-reflective storytelling, and AI-assisted media production
Participants	CaLD migrants with disabilities, Community leaders, disability advocates, peer support advocates, representatives from service providers and the technology industry	CaLD migrants with disabilities (subset of Stage One participants)

timelines, they also created opportunities to refine participatory engagement strategies, allowing the research to be responsive to participants’ lived realities (Cargo and Mercer, 2008; Nind, 2020). Furthermore, as the research progressed, the transition from lockdowns to more flexible in-person interactions deepened the understanding of participants’ everyday consumer technology use. These iterative adaptations strengthened the participatory nature of the research and allowed data collection methods to remain inclusive, flexible, and aligned with participants’ lived experiences. Specifically, the research process itself was reflexively adapted through participant-led refinement of accessibility strategies and engagement practices (Nind et al., 2022). One participant (Nidhi) played a key role in shaping these adaptations through sustained collaboration with the research team.

Building on participatory research principles, the ADDEPT project is also grounded in an intersectionality-informed framework, recognizing that overlapping systems of oppression, such as ableism and linguistic exclusion, shape participants’ engagements with everyday consumer technologies, while foregrounding agency by highlighting how individuals resist, adapt to, and negotiate these constraints in everyday life (Crenshaw, 1991; Collins, 2022). Intersectionality and participatory research complement one another by both recognizing CaLD migrants with disabilities as knowledge producers and challenging deficit-based narratives that frame them as passive recipients of technological assistance rather than as capable navigators and users of technology. This methodological approach disrupts such narratives by emphasizing participants’ agency in knowledge production and employing multiple modes of engagement, including creative workshops, individual interviews, and AI-generated e-book publications, to center their lived experiences as sites of knowledge production. Drawing on Collins’ (Collins, 2019, 2022) conceptualization of lived experience as a source of knowledge, this paper demonstrates how participatory and intersectionality-informed methods can facilitate agency, self-determination, and empowerment in research design. By centering lived experience as expertise, this paper captures how participants navigate, adapt, and redefine accessibility and digital inclusion on their own terms: not as passive subjects, but as active agents shaping their own digital environments.

2.1 Participants

Stage Two of the project included 11 CaLD migrants with diverse racial, cultural and linguistic backgrounds, as well as

differing migration experiences (e.g., first- or second-generation Australian) which were a subset of those from Stage One. Participants also represented a broad spectrum of disabilities including intellectual, visual, neurological, psychosocial, and physical impairments, reflecting intersections of CaLD migrant identity and disability. Although English was the shared working language, it was not the first language for most participants. Language represented in the project included Vietnamese, Hindi, Arabic, and Cantonese. However, none of the participants requested interpreters for their participation in project activities. Of the 11 participants in Stage Two, this article focuses on five participants whose contributions to the co-creation of AI-generated e-books provide the basis for the case study findings. Detailed profiles of these five participants are presented in the Results section. For clarity, although the participant sample included both CaLD migrants (first-generation) and individuals from CaLD backgrounds (second-generation), we use the term “CaLD migrants with disabilities” throughout this article as a collective descriptor, consistent with the framing of the project.

While all participants are classified as CaLD migrants, it is important to acknowledge that their migration histories and social positions varied significantly which shaped their distinct experiences of digital exclusion and accessibility barriers. For example, migrants with disabilities from racialized backgrounds often face compounded barriers related to racialization, language, and disability in their interactions with everyday consumer technologies and AI-generated representations. In contrast, European migrants from non-English-speaking backgrounds may still experience linguistic and cultural adaptation challenges but are not subject to the same racialized exclusions that non-European CaLD migrants encounter. Furthermore, the category of CaLD migrants in this study also includes individuals born in Australia who actively navigate cultural and linguistic diversity in their daily lives due to familial and community ties. For example, one of the participants, Mani, was born in Australia to parents who migrated from Vietnam. While not a migrant himself, his lived experience is shaped by cultural and linguistic practices that are distinct from those of English-dominant, Anglo-Australian peers. These distinctions are critical for understanding the ways in which structural biases and exclusion are embedded within everyday consumer technologies, AI-generated representations, and accessibility frameworks, all of which operate differently across various social locations. Applying an intersectional lens, the ADDEPT project recognizes that CaLD migrants with disabilities are not a homogenous group, and their experiences with technology, accessibility, and representation are shaped by

intersecting social positions including race, language, migration histories, and disability.

Participants were recruited through partner organizations including the Western Sydney Migrant Resources Centre (WSMRC) and YourSide which leveraged their networks to identify potential participants for the ADDEPT project. These organizations approached potential participants via email, providing them with detailed information about the project. Once individuals expressed interest and provided consent, the research team conducted follow-up phone calls to discuss the project further and address any questions. Participants were then sent a participant information sheet in plain English 1 week before participation to ensure they had ample time to review the material and seek clarification.

2.2 Data collection

Data collection methods were adapted significantly to accommodate participants' needs, minimize burdens, and address challenges posed by COVID-19 lockdowns, as outlined in the sections below (see also [Table 2](#)).

2.2.1 From self-documentation to interactive engagement (phase 3)

Initially designed as a digital self-documentation study, Phase 3 aimed to capture participants' daily technology use across various spaces and activities through personal recordings. To achieve this, Phases 3 incorporated a two-part process: (1) workshops to develop participants' digital self-documentation skills and (2) independent self-documentation where participants recorded their daily technology use through photos, text notes, videos, voice memos, applying the skills learned in the workshops. This approach was essential to align data representation with participants' self-representations, respecting their engagement with technology across diverse digital and physical environments ([Trace and Zhang, 2019](#)).

However, many participants found the self-documentation burdensome and stated that recording their daily technology use felt overwhelming and difficult to maintain. Given these challenges, the research team replaced self-documentation with one-on-one interviews and peer discussions, which allowed participants to share their experiences in a more structured and supportive format. To further enhance data collection and provide a comprehensive representation of participants' engagement with everyday consumer technologies, a local disability film and production team was contracted to document participants' technology interactions. These one-on-one interviews, peer discussion and film and media documentation complemented one another and ensured multifaceted depiction of participants' lived experiences. Additionally, this adaptation allowed researchers to gather rich qualitative insights into real-life technology use among CaLD migrants with disabilities, while reducing participant burden by providing alternative ways of expressing technology engagement beyond self-documentation.

COVID-19 restrictions further led to a complete re-design of Phase 3, requiring workshops to move online. For many participants, these online workshops were their first experience with group-based digital learning which demanded continuous adaptation to meet both educational and research objectives ([Miller and van Heumen, 2021](#)). Additionally, the prolonged use of virtual platforms contributed to "Zoom fatigue" ([Nesher Shoshan and Wehr, 2022](#)), further exacerbating participant burden. To address these barriers, the research team shortened workshops from 4-h sessions to 90-min sessions. When COVID-19 restrictions lifted in 2022, the research team attempted to return to in-person workshops. However, ongoing public health orders continued to limit large gatherings, which required additional adjustments. First, the venue was shifted from the art gallery to a larger university learning space to comply with health regulations and accommodate social distancing requirements. Second, in-person workshops were restructured into small groups of two to three participants to align with health guidelines and also encouraging more collaborative interaction and enhanced engagement. These adaptations in Phase 3 facilitated a more participant-centered approach by prioritizing accessibility and flexibility to support participant engagement ([Cargo and Mercer, 2008](#); [Nind, 2020](#)), while remaining responsive to evolving public health measures.

2.2.2 Evolving digital storytelling and AI-generated narratives (phase 4)

Phase 4 was originally designed to help participants curate their self-documented materials from Phases 3 and transform them into personal digital galleries through four-hour in-person workshops facilitated by community art professionals specializing in e-book storytelling. However, since the self-documentation component in Phase 3 was removed, the process of Phase 4 was restructured. Without pre-recorded materials to work with, the workshops become more structured and guided to help participants explore alternative ways to express their everyday consumer technology experiences. Instead of independent curation, participants engaged in facilitated discussions and creative exercises with community art professionals providing additional support. Before each workshop, sessions were re-designed to promote participant's artistic and creative expression to explore and distill their daily use of everyday consumer technologies. The use of creative methods was thought to operate as an enabling device to enhance participant communications through drawing and discussion ([Kramer-Roy, 2015](#)). However, as workshops progressed, participants responses to creative methods varied significantly. Some participants found drawing and visual storytelling to be effective and engaging and were able to map out their engagement across multiple digital platforms, sites, and applications. For instance, [Figure 1](#) illustrates a participant's ability to visually represent their technology use in a structured and meaningful way. In contrast, other participants struggled to capture their experiences through artistic methods and found drawing cumbersome and ineffective in conveying their personal technology interactions. [Figure 2](#) demonstrates these challenges where a participant attempted to illustrate their journey with video-gaming and how it supported their process of learning to drive. Despite their efforts, the drawing did not fully capture

TABLE 2 Summary of methodological adaptations in Stage Two (Phases 3 and 4).

	Original plan	Adaptation	Reasons for the adaptation
Phase 3	Self-documentation	One-on-one interviews, peer discussions, and film/media documentation	Self-documentation was overwhelming and difficult to maintain
	Four-hour workshops	90-min workshops	Zoom fatigue
Phase 4	Independent digital media creation based on self-documented materials	Guided discussions, peer-sharing activities, and interactive facilitation	Needed new ways after self-documentation removal and some found drawing ineffective
	N/A	Addition of post-workshop one-on-one and peer interviews	Creative methods alone were insufficient for some participants

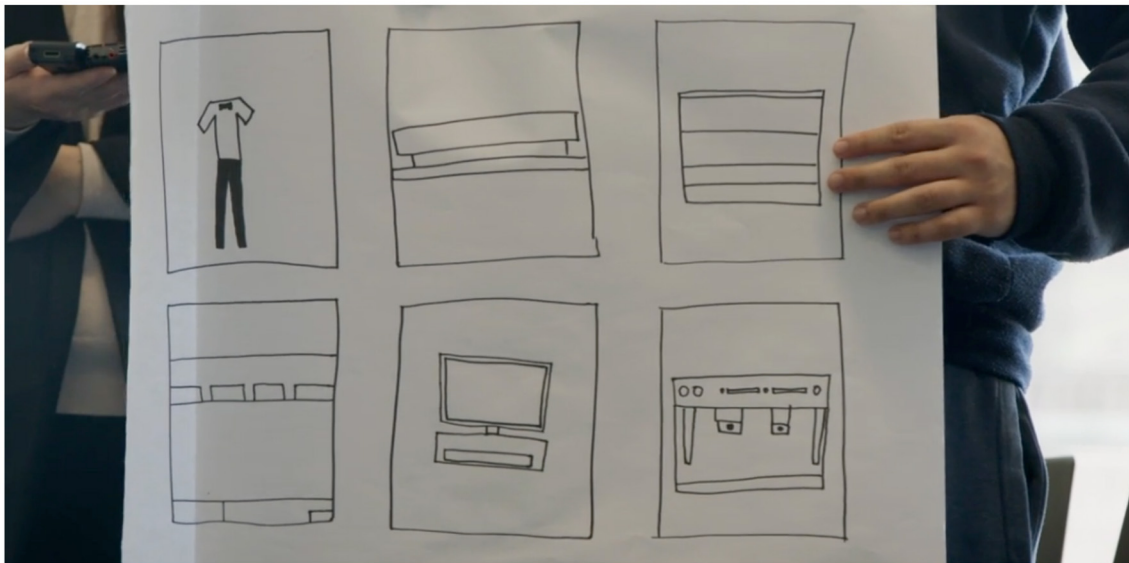


FIGURE 1
A participant displays their drawings from a workshop. The drawing depicts concisely how they use digital technology in several ways throughout their day-to-day activities.

their experience, highlighting the limitations of creative methods for some participants.

Recognizing these challenges, the research team modified workshop content to ensure more inclusive and accessible engagement of all participants. Additional methods including guided discussions, peer-sharing activities, and interactive facilitation techniques were incorporated to better support participants who found artistic methods difficult. Through this iterative process, workshops evolved dynamically and ensured each session was tailored to participants’ needs and learning styles.

2.2.2 Introduction of post-workshops interviews

Another key adaptation in Phase 4 was the addition of post-workshop interviews to address participants’ difficulties in expressing their experiences solely through creative workshops. These interviews were conducted in two formats: (1) one-on-one interviews prior to workshops to allow participants to reflect on their experiences and share insights into their everyday consumer technology use and (2) one-on-two peer-interviews which enabled participants to engage with others who shared similar lived experiences. While all interviews followed the same two *primary*

questions, ‘How do you use technology?’ and *What problems do you have with using technology?* they allowed interviewees to expand on their responses and provide personalized demonstrations of their technology use and experiences.

A critical finding from the first set of post-workshop interviews was that more than half of participants had limited understanding of AI and its implications for their everyday technology use; the key idea within the ADDEPT project. Since AI was central to Phase 4’s focus on co-creating AI-generated e-books, the research team redesigned the workshop materials to enhance accessibility and comprehension. The revised materials included an Easy English information booklet with visual cues designed to provide a clear and simplified explanation of AI concepts to ensure that participants had a stronger foundational understanding of AI before engaging in AI-generated e-book co-creation activities.

2.2.3 AI-generated e-book co-creation

After the completion of the data collection process across both rounds of workshops (online and in-person) and post-workshop interviews, the research team collaborated with five participants, whose details are provided below in each of the

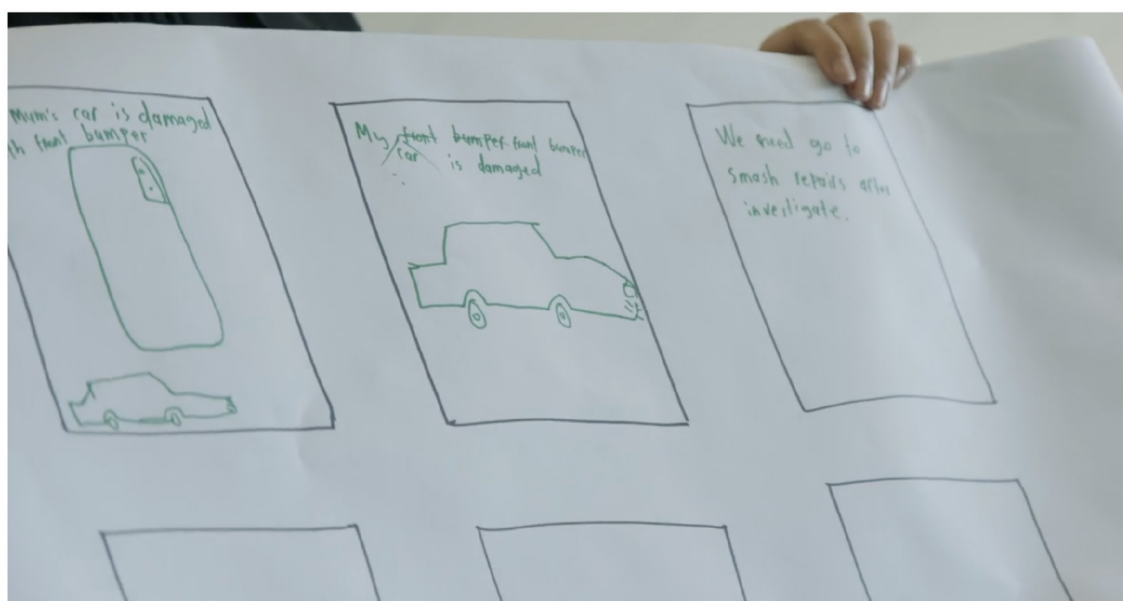


FIGURE 2

A participant displays their drawings, created during the workshop, to describe their experience with video gaming and its association with their future driving competency.

case studies, to co-create multilingual, disability-accessible AI-generated e-books. The co-creation activities were conducted using MidJourney a generative AI program and took place between November 2022 and October 2023 during which MidJourney Versions 4 and 5 were used. As AI tools evolve rapidly, the e-books described in this paper reflect a specific snapshot of generative AI capabilities during that period. Using this platform, these e-books visually and textually represented participants' experiences with everyday consumer technologies. Beyond documenting personal experiences, the co-creation journey provided insights into participants' technological engagement and accessibility needs. First, we learnt about (1) the barriers in navigating digital accessibility and the burden of self-advocacy, (2) the biases embedded in AI-generated imagery, especially in relation to gender, race, disability, age, and body weight, and (3), the role of everyday consumer technologies in fostering agency through self-directed learning, cultural engagement, mobility, and caregiving support.

Contrary to deficit-based narratives that frame CaLD migrants with disabilities as digitally incompetent, participants demonstrated agency, creativity, and resilience in their everyday consumer technology use. Rather relying on external assistance, they actively engaged in peer knowledge-sharing, such as CaLD migrant children teaching their parents how to use new technology, fostering collective empowerment. The following case studies of technology and its multifaceted role in accessible participation, AI prejudice, language skill building, and independent mobility, provide a rich collection of learnings from our co-created research.

3 Results

Stage Two of the ADDEPT project was designed to explore how CaLD migrants with disabilities engage with everyday consumer

technologies and how AI-generated media representations reflect their lived realities. While intersectionality served as a central theoretical and methodological framework, participants were not explicitly promoted to frame their experience through the lens of multiple intersecting identities such as gender, race, language, disability, age, and body weight. Instead, they were encouraged to narrate their experience in ways that were most relevant and meaningful to them. Each case study highlights a distinct dimension of identity, technology engagement and the challenges participants faced. Table 3 outlines the participants and primary identities that were most explicitly discussed in each case. However, it is important to acknowledge that all cases reflect intersectional lived realities; even when participants foregrounded one identity, their narratives inherently reflected the simultaneous navigation of multiple identities and associated systemic barriers (Bowleg, 2008).

Five participants were involved in the following case studies and co-created AI-generated e-book publications to support accessible knowledge dissemination about their use of technology. These participants and their co-created e-books are introduced below in order in which they appear in the case study findings:

Nidhi is a CaLD migrant woman (first-generation) from India with a physical disability and vision impairment in her 20s. She is a disability advocate for a multicultural disability organization in a low socio-economic area of Sydney with significant professional responsibilities in her role and uses technology in both her personal life and career.

Leza is a multi-generational white settler Australian woman (second-generation) in her 30s with intellectual disabilities. She lives in a disability-supported residence alongside four housemates and several caregiving staff. She enjoys

TABLE 3 Participants, primary identities, and key themes in each case study.

Case Study	Highlighted participant(s)	Highlighted identities	Key themes
Case One: <i>Navigating Digital Accessibility</i>	<ul style="list-style-type: none">• Nidhi	<ul style="list-style-type: none">• Language• Disability	<ul style="list-style-type: none">• Digital accessibility challenges• Multilingual accessibility gaps• Burden of self-advocacy
Case Two: <i>AI Bias and Misrepresentation</i>	<ul style="list-style-type: none">• Nidhi• Leza• Sadie	<ul style="list-style-type: none">• Gender• Race• Age• Disability• Body weight	<ul style="list-style-type: none">• AI-generated image misrepresentation• Default aesthetic norms and bias in AI
Case Three: <i>Everyday Consumer Technology and Agency</i>	<ul style="list-style-type: none">• Mani• Laurance	<ul style="list-style-type: none">• Language• Disability	<ul style="list-style-type: none">• Assertion of agency through technology• Technology as a tool for self-directed learning, cultural exploration, mobility, and caregiving support

using technology for activities such as Google, YouTube, email, computer games, as well as for participating in online communities.

Sadie is a CaLD migrant gender-neutral person (first-generation) from Lebanon with intellectual disabilities and vision impairment in her 50s. She resided with her mother. She and her extended family had migrated to Australia in her earlier life. She spoke both English and Arabic, with Arabic being the primary language spoken at home. She loved using Facebook and Messenger to connect with and view photos of her family and friends. She sadly passed away before this project was completed, in September 2023. Her friend, Leza, contributed largely to the co-creation of Sadie’s story.

Mani is an Australia man (second-generation) in his 20s with parents who migrated from Vietnam with intellectual disabilities. He speaks Vietnamese and English. At the time when the workshops were conducted, Mani resided in his family home with his parents and sister. He loves technology, and uses it diversely: exploring interests, making friends, learning a language, and helping his family with different online platforms.

Laurance is an Australian man in his 20s (second-generation) with parents who migrated from China living with neurodivergence. He speaks Cantonese and English, with English being his main language, but at home, his parents speak to him in Cantonese. He uses technology to explore his interests, to teach important skills such as driving, and to provide some practical support to his parents.

3.1 Case one: navigating digital accessibility

“I think often we hear about sort of making things accessible as though there is just sort of one pathway to doing that but of course, accessibility means very different things for different people. For me, accessibility with vision impairment means translating in Braille, translating audio. It also means translating documents in large print and making the font size larger. It can also mean that you know I used to have things

voice recorded as an accessibility format. All things being read out to you by Voiceover on documents and then read out to you as a template email synthetic voice.”

Nidhi

Nidhi, who described herself as a CaLD migrant (Indian background) with a physical disability and vision impairment, navigated overlapping systems of exclusion that shaped her engagement with everyday consumer technologies and AI-generated content. As part of the project, Nidhi participated in testing AI-generated e-books (Phase 4) to assess their accessibility for CaLD migrants with disabilities. Her testing revealed significant usability challenges regarding screen reader compatibility and multilingual accessibility. While Nidhi did not experience linguistic barriers herself, as her primary language is English, her insights underscored how accessibility features are often designed with English-dominant users in mind and overlook the diverse needs of multilingual individuals with disabilities.

Nidhi’s experiences with everyday consumer technologies provided a foundation for evaluating AI-generated accessibility tools. Having long relied on digital platforms for mobility, communication, leisure and professional advocacy, she had firsthand knowledge of the barriers that individuals with vision impairments face in navigating such technologies. Over the 2-years fieldwork period, Nidhi brought attention to accessibility gaps in mainstream technologies.

“I am vision impaired and use a Samsung phone and an iPad and can use Zoom successfully, but I will need closed captions and all Zoom connection details via dial-in and the link sent to me via email...”

Nidhi’s self-disclosure and open sharing of her accessibility needs provided important information for the research team in preparing workshops and co-creating AI-generated e-books. Nidhi provided details not just about her take up of everyday consumer technologies but also, had learnt to give clear instructions of what was required to facilitate this each step of the research. Even though the research team had prepared a set of questions in relation to technology use, capability and challenges in pre-workshop interviews to ascertain accessibility needs of each participant, it

was ultimately Nidhi who had to instruct, negotiate, and advocate each step of the process, an experience commonly reported by individuals with disabilities (Konrad, 2021).

Through these discussions, it became clear that the everyday consumer technologies and AI-generated e-books presented overlapping accessibility challenges. For example, while Nidhi was able to read text on digital platforms, she found it very difficult to see images and often relied on voice-over features to navigate her digital devices. Additionally, her screen reader was incompatible with certain platforms, such as Microsoft PowerPoint. She pointed out that she was required to convert PowerPoint presentations to Word or other formats to be compatible with her screen reader software. Nidhi's continued participation in the workshops revealed how non-user-centered accessibility forces individuals with disabilities to be highly adaptive at the expense of ease and efficiency. Her experiences echoed research findings that accessibility accommodations are considered "justifiably excludable", and are therefore "justifiably absent" from mainstream digital infrastructures (Titchkosky, 2011; Konrad, 2021).

"We never get accessible information in our own accessible format. You go around and ask 'are you happy with the information in the format?' 'Usually it is no. Translating resources in different information, to braille, audio and voice recording, voice out, text size accessible content - formal [language] translation, organizations say they don't have time or funding."

As such, fatigue around communicating access in daily life is a recurring experience for people with disability, because requesting and obtaining appropriate access requires several people with disabilities which have been described by Konrad (2021) as performing "publicly suitable" disability, navigating reactions to disability, negotiating the value of accessibility with others, and the pedagogical responsibility, wherein individuals with disabilities must teach others about accessibility in order to obtain it. There is therefore a significant emotional, mental, and physical burden of access for people with disabilities, which serves as an additional barrier to achieving and using day-to-day technology, and underlies the partially-accessible nature of much digital technology (Konrad, 2021).

What we will see in future cases described in this study, is the exacerbating impact of additional barriers caused by intersecting identities which affect an individual's ability to negotiate accessibility (Konrad, 2021; Mack et al., 2022; Reyes-Cruz et al., 2020). Accessibility requires continuous, clear communication; yet for CaLD migrants with disabilities whose primary language is not English, this process is further complicated by language barriers, placing an even greater burden on them to articulate and negotiate their access needs (Mack et al., 2022; Rink, 2024). Such Anglo-centric technological infrastructures privilege Western, English-speaking users, further widening the digital divide. As a result, CaLD migrants with disabilities often must self-navigate, adapt to, and compensate for inaccessible designs rather than having their needs systematically addressed (Goggin and Soldatic, 2022; Ned et al., 2024).

In summary, Nidhi's experience highlights a fundamental limitation in digital accessibility framework: while many technologies incorporate accessibility features such as screen readers, these tools are often incompatible across different platforms, therefore, users must manually adapt their workflows. Standardized accessibility solutions are deemed to be designed with a one-size-fits-all approach while failing to accommodate the diverse needs of individuals with different types of disabilities. Furthermore, Nidhi's observations underscore the linguistic exclusivity of many accessibility tools, which prioritize English and offer limited support for other languages. This means that users are required to switch platforms or rely on external sources such as Google Translate, to navigate and comprehend digital content. These challenges are particularly pronounced for CaLD migrants with disabilities, especially those with vision impairments who do not primarily speak English.

To address the accessibility barriers in co-creating AI-generated e-books in Phase 4, the research team adopted a user-led adaptation by actively collaborating with Nidhi to develop solutions that suited her needs and preferences. Throughout the research journey, a research assistant maintained ongoing follow-ups with Nidhi to address any access issues and adapt research materials as needed. Proactive strategies, such as phone calls were used to increase the accessibility and transparency of information, while also building rapport. Nidhi's engagement with digital platforms further demonstrates the needs for participant-driven accessibility solutions. During the first workshop, Nidhi openly shared her preference for using Facebook as a documentation tool rather than Padlet, which had been provided by the research team. Although Padlet met all Nidhi's accessibility requirements, her preference highlighted a gap in accessibility design: even when a tool is technically accessible, its unfamiliarity can create an additional barrier. Through ongoing, proactive communication, the research team adjusted documentation methods based on Nidhi's feedback and adopted Facebook as the main documentation tool instead of Padlet to better align with her existing digital practices. It should be noted that while these strategies were adapted by the team to ensure a smooth and adapted process to best suit Nidhi's needs, this ease of communication and enhanced efforts toward accessibility are often absent in everyday consumer technologies, and even in research and academic contexts (Isaacson, 2021; Konrad, 2021). This underscores the need for accessibility framework that go beyond compliance and instead prioritize user-driven, contextually adaptive solutions that integrate accessibility meaningfully integrated into technological design and research practice.

In conclusion, Nidhi's experiences navigating digital accessibility revealed gaps in mainstream accessibility frameworks. While many platforms claimed to be "accessible", her engagement with everyday consumer technologies and AI-generated e-books exposed persistent barriers in screen reader compatibility and multilingual access. Even when accessibility features are available, they are often inconsistent, difficult to navigate, and linguistically exclusive. Ultimately, Case One provided critical insights into digital accessibility which set the stage for Case Two which expands on these discussions by examining of AI-generative images and explores the biases embedded in AI-generated visuals showing how

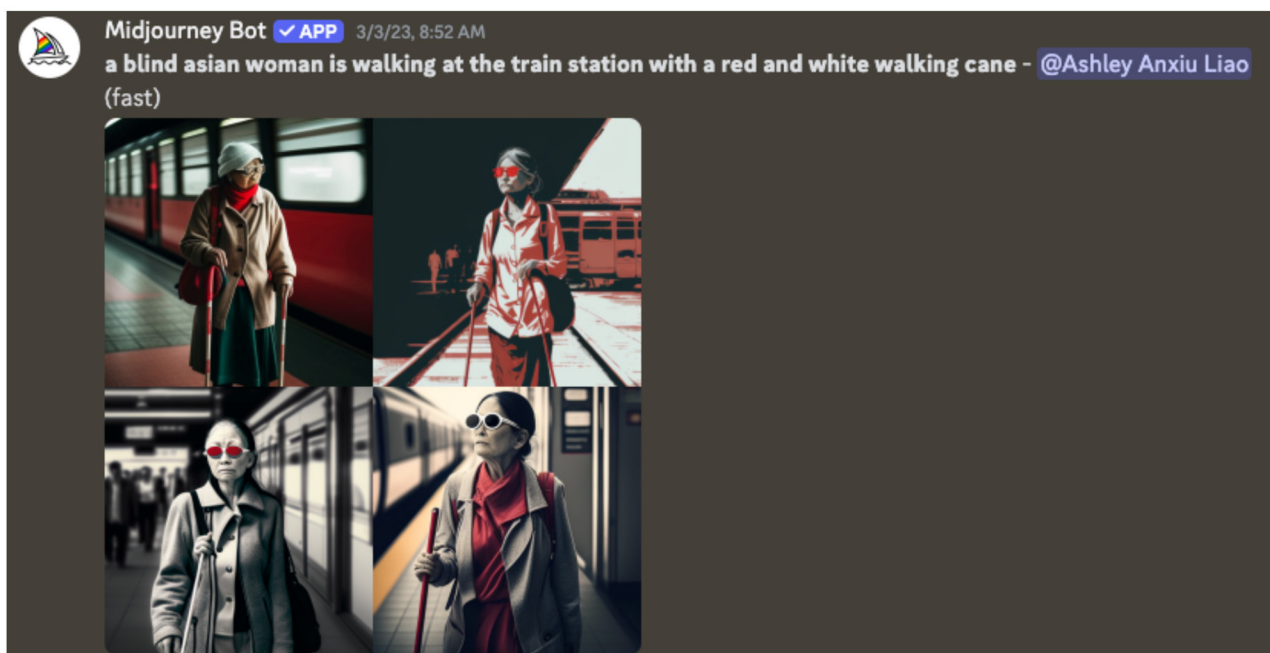


FIGURE 3

A screenshot of one of the preliminary visual image outputs from generative AI. The images display an elderly East Asian woman walking with a cane and dark glasses.

generative AI perpetuates systemic biases in gender, race, disability, age, and body weight representation.

3.2 Case two: AI bias and misrepresentation

Despite advancements in AI and machine learning, generative AI systems continue to reproduce and amplify societal biases, especially when representing individuals who experience multiple, intersecting forms of exclusions. This case study explores how AI-generated misrepresentation of gender, race, disability, age, and body weight shaped the digital portrayals of Nidhi, Leza, and Sadie, and highlights the systemic limitations of AI in representing diverse identities without perpetuating existing social hierarchies.

3.2.1 Journey of co-creation with Nidhi: “autonomy, freedom, and mobility”

During the co-creation of an experience-based AI-generated e-book, Nidhi, a visually impaired disability advocate of Indian background, faced several challenges while creating AI-generated images that accurately represented her intersecting identities (Shekaran et al., 2023).

Figures 3–5, the AI visualizations created for Nidhi, reveal that the AI system interpreted descriptive terms including “woman”, “Asian”, and “blind” through a lens of preconceived biases. Specifically, the Figure 3 demonstrates the AI’s automatic association between gender, race, disability, and aging and depicts Nidhi as an elderly woman, despite no age-related descriptor being included in the prompt. This suggests that AI visualization tools

reproduce dominant societal narratives that equate the intersection of Asian women with disabilities with older age, rather than recognizing disability as a lifelong or otherwise acquired earlier in life.

To address these inaccuracies, the research team refined the input descriptors by adding terms such as “professional” and “smiley” to better reflect Nidhi’s self-identification. However, this introduced another layer of bias (see Figure 4): the AI began generating images of individuals presumed to be of East and Central Asian descent, indicating long-held stereotypes around the category of peoples from this geographical location (East and Central Asia), where East and Central Asian people are considered “more Asian” and that South Asian people are less Asian, or not considered Asian at all. Public rhetoric calls out the targeted position of South Asian communities, such that race and colorism impacts their experience of Asian identity in AI-generated representations. Within these systems, South Asian identities are frequently marginalized or rendered invisible, as dominant data sources and algorithmic training sets privilege lighter-skinned East and Central Asian phenotypes as the default “Asian” representation. This reproduces and reinforces existing racial hierarchies within the category of “Asian”, compelling users to engage in additional labor to assert the visibility and accuracy of their identities.

The most accurate representation (Figure 5) was only achieved after explicitly detailing every aspect of Nidhi’s identity including her disability, profession, and self-perceived characteristics, demonstrating that to authentically represent diverse identities, it requires the users to over-specify attributes to counteract the pre-existing biases within the algorithm. Ultimately, the burden



FIGURE 4

A screenshot of another attempt at generating a visual representation of Nidhi. The images display only East Asian women.

falls on users to “correct” intrinsic biases to generate accurate depictions of their intersecting identities.

3.2.2 Journey of co-creation with Leza: lifelong learning and remembering Sadie Daher

Like Nidhi, Leza and Sadie encountered significant challenges in generating AI images that accurately reflected their intersecting identities. This section explores how AI’s default aesthetic norms and embedded biases influenced their digital representations, requiring extensive prompting and user intervention to achieve more accurate portrayals (Grundy et al., 2023).

3.2.2.1 About Leza

Leza resided in a disability-supported accommodation for persons with intellectual disabilities with four housemates and had minimal contact with family members. She identified her cultural background as Australian, specifically as multi-generational white settler Australian. Her engagement with everyday consumer technology was shaped by both personal interest and structural constraints with her living environment. Leza experiences with technology were mixed. She owned a computer and a smartphone, which she used for leisure and entertainment, such as watching YouTube videos and listening to music. She appreciated YouTube’s personalized recommendations and keyword search functions which allowed her to curate content based on her interests. However, her technology use was closely monitored by house staffs, especially regarding social media, email access, and online communication platforms. While this is a commonly encountered form of online risk mitigation and safety measures taken by caregivers of individuals with developmental or intellectual disabilities, they contributed to

feeling of restriction, digital exclusion, and a lack of autonomy (Chadwick, 2022).

3.2.2.2 Co-creation of stories with Leza

Two years after the initial workshops, Author Ashley Liao visited Leza at her shared home to co-create her AI-generated e-book. As part of this co-creation process, photographs of Leza, her computer, and her screen were taken to inform the development of AI generated images. However, the AI-generated images had the tendency of making the image of her character look like a ‘Barbie doll’, which did not reflect her identity nor her preference. This Barbie doll-like depiction exemplifies stereotypical portrayals of femininity, projecting Eurocentric body ideals shaped by the intersection of whiteness and sexism, which have been critiqued for perpetuating narrow, hyper-feminized and exclusionary standards of women (Sutko, 2020). To counteract this bias, the research team continuously refined the AI prompts with Leza’s ongoing feedback. The final prompt was structured as: “a chubby young woman with short blond hair, wearing long and large earrings and a beaded necklace, bracelets, in a red T-shirt, holding a laptop with a big smile, standing” (Figure 6). Despite these refinements, the AI-generated images continued to misrepresent Leza’s self-image. To ensure that readers saw an authentic representative image of Leza, she ultimately chose to use her personal photograph for the book cover, while incorporating AI-generated images throughout the internal pages.

Leza’s experience highlights the persistence of AI biases that conflate womanhood with hyper-feminization, thinness, and Eurocentric beauty ideals. It also demonstrates the labor required by users to repeatedly intervene and correct algorithmic misrepresentations.

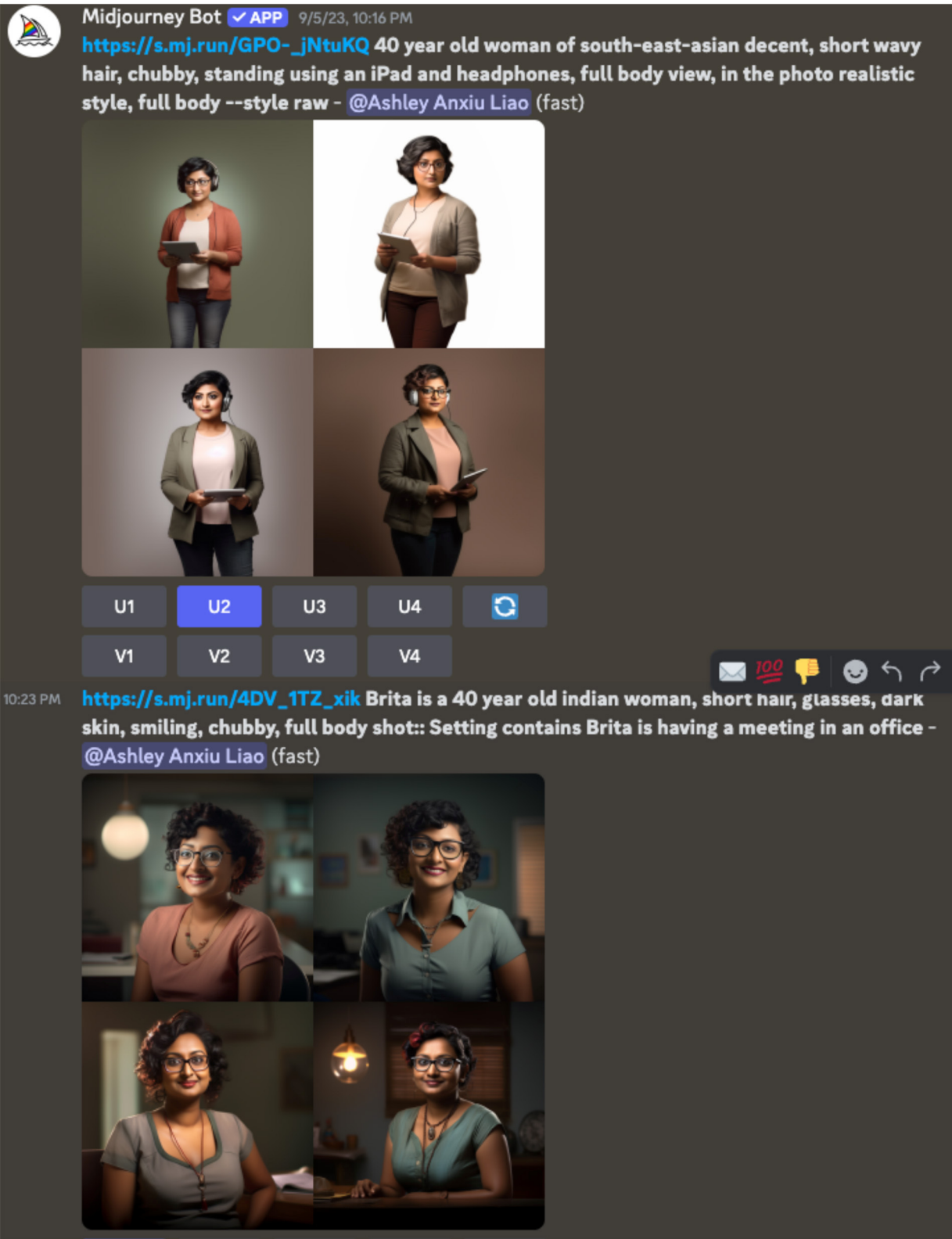


FIGURE 5
The final iterations of AI generative visualizations of Nidhi, using detailed, explicit descriptors.

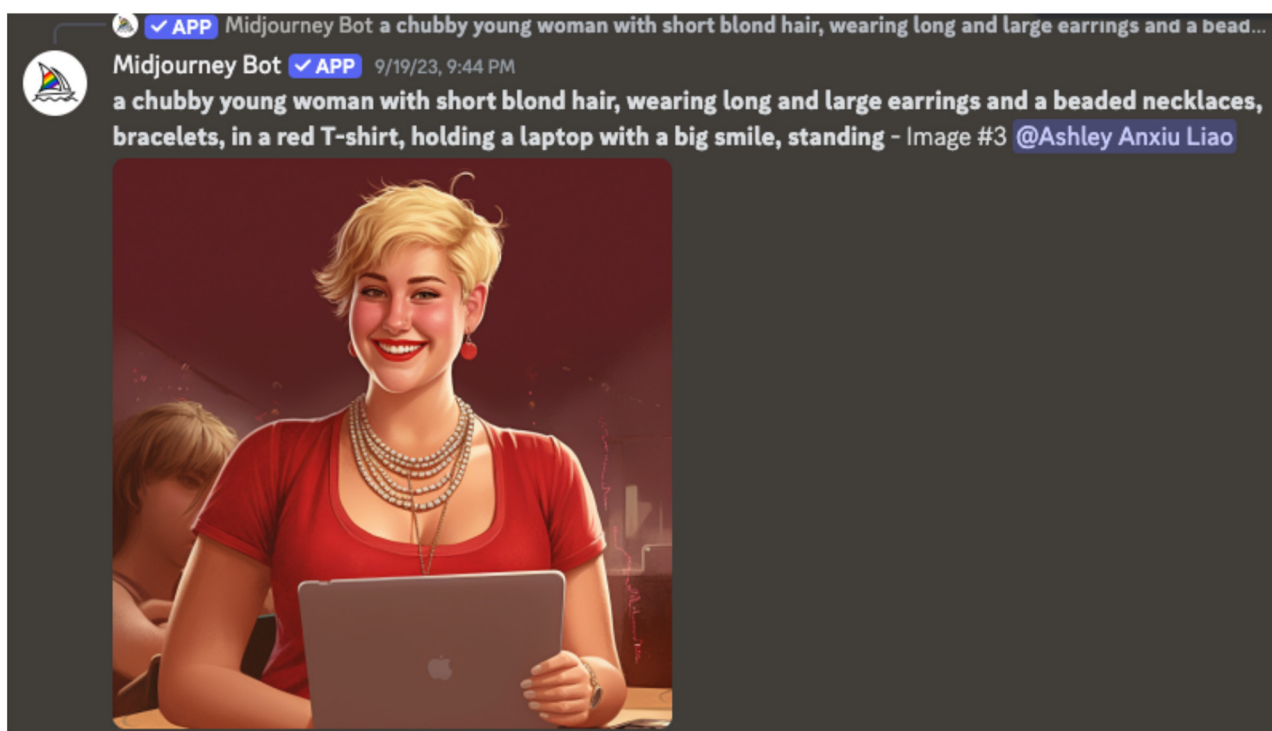


FIGURE 6

A screenshot of the final visual output agreed upon by collaborators to represent Liza, after significant difficulties in AI generation of a representative image of Leza's "true" self.

3.2.3 Remembering Sadie: technology, family, and representation

3.2.3.1 About Sadie

Sadie lived with her mother and came from a Lebanon-Australian background, having migrated to Australia with her extended family during childhood. She is bilingual, speaking both English and Arabic, with Arabic being the primary language spoken at home. While her siblings had since moved out to start their own families, Sadie remained connected to them through everyday consumer technologies. Sadie particularly valued Facebook Messenger because she could access the photos of her nieces and nephews and participate in family conversations using emojis. Her digital interactions with her family were often conducted in both English and Arabic, demonstrating the linguistic and cultural integration within her family network. This aspect of family interaction via digital technology was important to Sadie, as it enabled her to connect with her family while living apart from one another. Despite living with an intellectual disability and restricted vision, Sadie did not identify these impairments as barriers to the use and enjoyment of everyday consumer technology. When asked if she found anything difficult about technology, Sadie always responded that she was unsure which suggest that her lived experiences of living at the intersection of South-east Asian gender-neutral person with disabilities did not hinder their digital participation in the ways often assumed by accessibility discourses.

During the project, as the team reached out to collaborate on her AI-generated e-book, Sadie was hospitalized with a severe

illness. Her siblings communicated on her behalf, shared her excitement about the storybook and consented for her name to be included. However, before the team could visit her with a draft, Sadie sadly passed away. The completed e-book was launched with her immediate family in attendance, including her mother, siblings, cousins, and extended relatives.

3.2.3.2 Co-creation of Sadie's stories with Leza

Following Sadie's passing, her close friend Leza played an integral role in contributing to Sadie's story by recalling memories of their shared experiences with technology and actively selecting AI-generated images to represent Sadie. A series of AI-generated portraits were produced using the prompt: "a chubby, small, south-east Asian gender-neutral person, 50-year-old, with short black hair, tanned skin, middle-part hairstyle, wearing a hoodie, on a video call on her laptop". These prompts were deliberately crafted to counteract potential AI biases in gender, race, and body representation that had been observed in Nidhi's and Leza's cases (Figure 7). Furthermore, the term "gender-neutral" was intentionally included to mitigate the risk of gendered bias in AI-generated representation particularly in hairstyle and clothing (Figure 7). However, despite specifying Sadie's age as 50 years old, the AI-generated images depicted them as significantly younger. This contrasts with Nidhi's case (see Figure 3) where AI automatically associated vision impairment with older age and portrays Nidhi as elderly despite no age-related descriptor being included. These patterns suggest that AI-generated visualizations rely on ingrained societal assumptions:

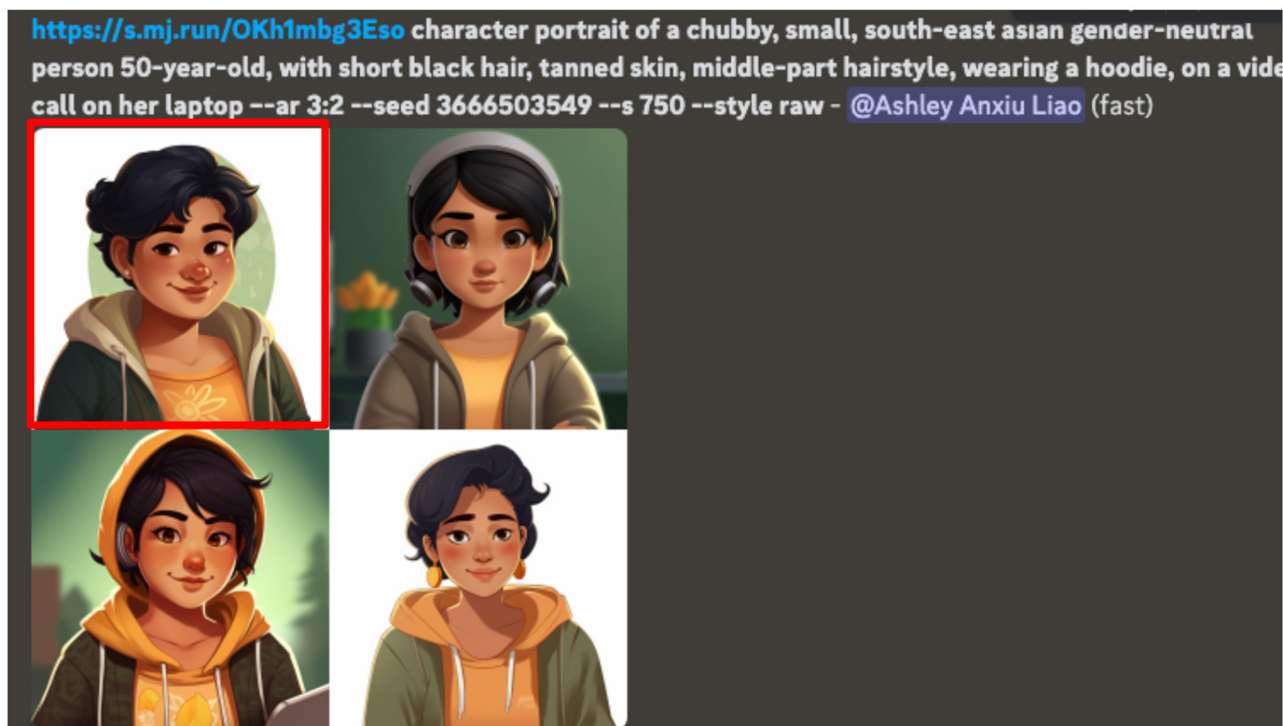


FIGURE 7

The final prompts used to create the AI image of Sadie, with the selected image for the books highlighted in red.

associating vision disability with old age in Nidhi's case while failing to recognize middle-aged individuals like Sadie unless they exhibit stereotypical aging features such as wrinkles or gray hair. After extensive prompts and discussion with Leza, the highlighted image in Figure 7 was selected as the most appropriate representation of Sadie which aligned with Leza's perspective and Sadie's family's wishes.

Ultimately, Sadie's case highlights the emotional, ethical, and representational complexities of AI-generated imagery in the context of digital memorialization. Furthermore, it raises questions about who gets to be represented, how identities are visually reconstructed, and what it means to create a digital legacy for those no longer present to shape it themselves.

Taken together, the AI-generated e-book co-creation process with Nidhi, Leza, and Sadie shows the complexities of AI-generated imagery, and the way algorithmic biases shape digital representation. While AI holds the potential for personalized and inclusive visual storytelling, Case Two shows how current generative models often perpetuate pre-existing societal stereotypes across multiple social identities including gender, race, disability, age, and body weight. Furthermore, it highlights the need for AI-generated imagery to prioritize diverse intersecting identities from the outset, rather than relying on users to correct systemic biases through repeated iterations, an issue criticized widely in discussion of how structurally disadvantaged individuals are often expected to advocate for their own inclusion (Konrad, 2021).

3.3 Case three: everyday consumer technology and agency

Everyday consumer technologies play a critical role in fostering self-directed learning, social engagement, and independence for CaLD migrants with disabilities. This case explores how Mani and Laurance, two participants with distinct technological engagement, used everyday consumer technology to navigate language learning, cultural connections, and mobility. Their experiences challenge dominant narratives that often depict CaLD migrants with disabilities as passive technology users, instead demonstrating their active participation in digital and physical space through such technologies, not only for personal development and as support providers for their families.

3.3.1 Journey of co-creation with Mani: "languages, learning, and inclusion"

The following case examines the lessons learned from co-creating "Languages, learning and inclusion" alongside Mani (Chung et al., 2023). Mani's story, as represented in his AI-generated e-book, highlights the role of technology in language acquisition and cultural engagement through AI-driven translation tools (e.g., Google Translation) and language learning application, Duolingo. His self-directed learning of Japanese and his role in assisting his mother in learning English demonstrate the reciprocal

Page 10



I have a group of friends who are like me. I have known them for a very long time. We all love watching Japanese anime online and Cosplay (custom play) from Japanese culture!

Page 11



I have made myself the customs of my favourite characters and dressed up to attend the Sydney Manga and Anime Show with my friends. I walked on the stage to show my cosplay character and lots of people took photos of me. It's most exciting to meet many people at the show who share my passion!

FIGURE 8

"Languages, learning and inclusion" (Chung et al., 2023). Mani describes his interests and his social community around anime and cosplay.

nature of digital literacy, where individuals with disabilities not only benefit but also facilitate technological engagement for those around them.

3.3.1.1 About Mani

Mani, who lives with an intellectual disability, was born in Australia with parents who migrated from Vietnam. He is bilingual in Vietnamese and English and is self-taught in Japanese. At the time when the workshops were conducted, Mani resided in his family home with his parents and sister. When COVID-19 restrictions eased, Mani's elder sister drove Mani and his mother to attend the in-person workshops held in the second year of the project. Mani had an active social life and attended various group programs designed for people with intellectual disabilities throughout the week, including a weekly computer-interest group. He also engaged with everyday consumer technology to learn language and to use social media networking. Mani shared his interest in Japanese culture and animation which influenced his self-directed efforts to learn Japanese through platforms such as Google Translate and Duolingo. In addition, Mani helped his mother, a native Vietnamese-speaker, learn English using such technology.

3.3.1.2 Co-creation of Mani's story

As part of the AI-generated e-book co-creation process, Mani's experiences with language learning and cultural engagement were central themes. During the workshops, Mani highlighted his recent achievement of creating and wearing costumes of his favorite video game characters (also known as "cosplay") which he presented on stage along with his friends at the Sydney Manga and Anime Show (Figure 8). This was included as an integral part of his story around everyday consumer technology, especially because of the strong involvement of the technology in developing these friendships and contributing to their shared interests in anime and video games. It also served to inspire and drive his creative costume in cosplay. Beyond cosplay, Mani's technological engagement was driven by his passion for Japanese culture and language. During post-workshop interviews via Zoom, he described his commitment to daily language learning using Duolingo and highlighted how the app's reminders helped him stay consistent in his practice every day (Figure 9) (Chung et al., 2023). His aspiration to visit Japan 1 day further strengthened his motivation to learn the language (Figure 9).

In addition to his own language learning, Mani played a unique role as a digital mediator for his family. He helped his mother, a native Vietnamese-speaker, in learning English. Through Duolingo,

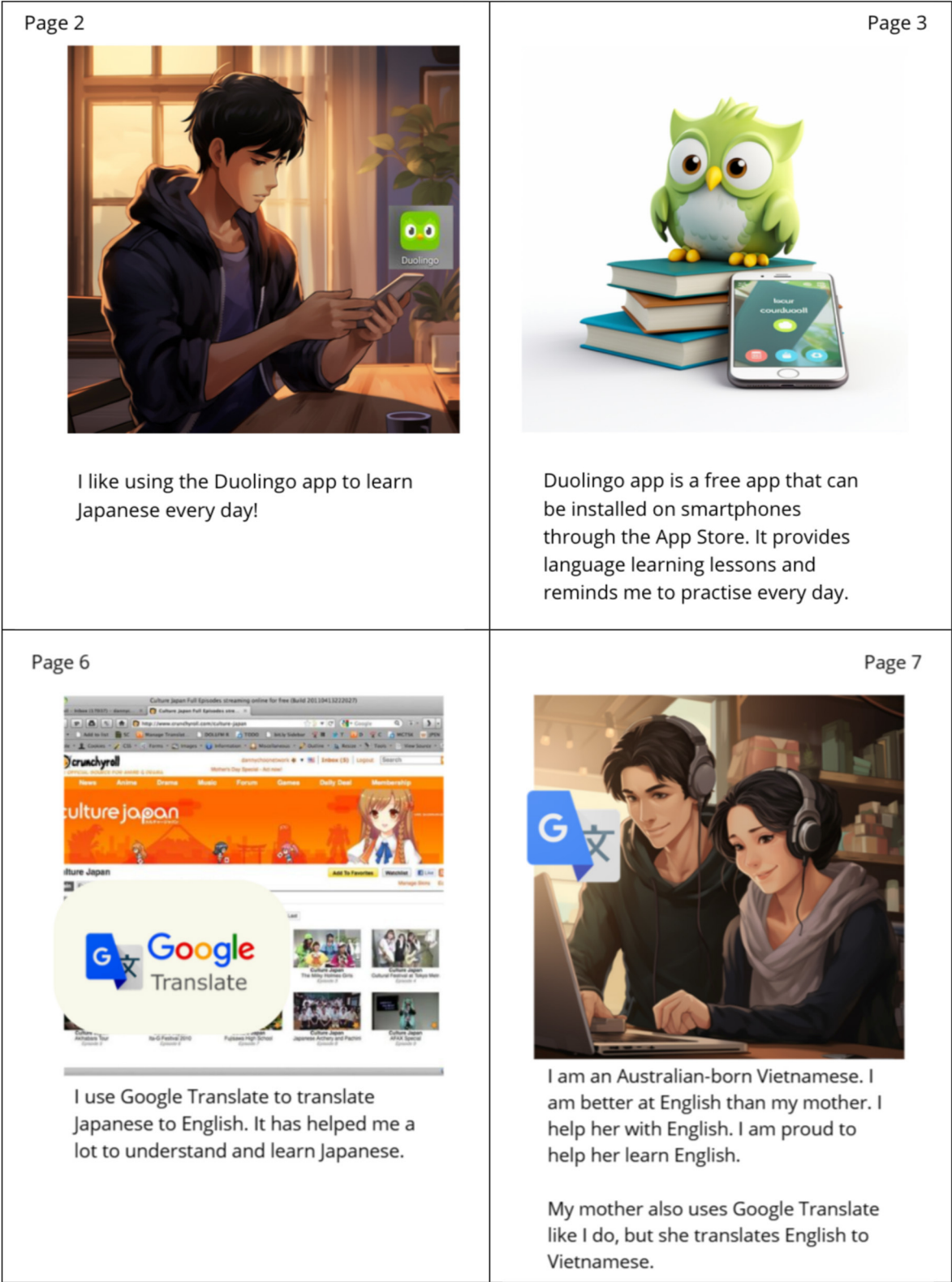


FIGURE 9
“Languages, learning and inclusion” (Chung et al., 2023). Demonstration of Mani’s use of Duolingo and Google Translate for language learning and teaching.

Mani guided her in navigating the app, answering educational prompts, and making sense of new vocabulary (Figure 9). Mani was very proud of his contribution to his mother's language development. He was also able to provide similar technological supports for many of his family members, helping them to navigate through unfamiliar software and platforms, including government websites, public transport apps, language learning apps, social media, Google Maps and their favorite mobile or digital games.

3.3.2 Journey of co-creation with Laurance: gaming, driving, and independence

Independent mobility in the context of disability was a strongly represented theme throughout this project. This section examined the stories of Laurance, whose lived experience with disability includes roles as both a care receiver, and a care giver, facilitated through digital technology (Trieu et al., 2023). As a bilingual individual, Laurance's relationship with technology extended beyond personal use. He played an active role in supporting his aging parents, challenging conventional assumptions of dependence. His story illustrates how individuals with disabilities can serve as key facilitators in their families' digital and mobility experiences.

3.3.2.1 About Laurance

Laurance is an enthusiastic and autonomous adult who lives with neurodivergence. Laurance has a keen interest in trains, cars and gaming. At the time he participated in the workshops, he was living with his family and preparing to enter the workforce. Alongside the research team, Laurance co-created the "Gaming, driving and independence" e-book (Trieu et al., 2023), which explored his evolving relationship with technology, mobility, and caregiving roles.

3.3.2.2 Communication

Laurance is bilingual in English and Chinese Cantonese. English is Laurance's main language, which he uses to receive auditory and written information. Laurance can express himself by speaking and writing in English. Laurance's expressive oral communication appeared at times to be at a basic level, when he spoke using short sentences, phrases or single words. Laurance's parents speak to him in Cantonese at home which he can understand, such as following instructions. At times, Laurance provides practical support to his parents. Often, individuals with disabilities are depicted as being hyper-dependent on caregivers, often ignoring many of the important and supportive roles that these individuals have in supporting those around them (Flynn, 2021). In many migrant communities, first-generation migrant parents will rely on their children for support in communicating with others in their new home; children act as language brokers and sociocultural mediators for their parents (Bauer, 2016; Orellana, 2009). Laurance and many children of migrants thus adopt a partial caring role at an age and in a way that most children of non-migrants may not experience (Orellana, 2009); this role persists even for a person experiencing intellectual or developmental disability.

3.3.2.3 Co-creation of Laurance's story

Throughout the workshops, Laurance demonstrated his intense interest in cars, trains and gaming. Not only were these interests frequently addressed during Laurance's participation of group activities and individual interviews, but Laurance was also observed to spend a significant amount of time during the workshops immersing himself in these interests via his iPad and phone. This included activities such as browsing car manufacturer information, looking up train timetables, and playing mobile games, using web browsers, apps, and a range of other media platforms. In the first workshop, Laurance demonstrated his technology usage through a drawing of himself using his phone to take photos of a car accident in which his mother was the driver, and he was a passenger and witness. Laurance later drew a conceptual design of a car, equipped with an autonomous driving function, with the aim of this function preventing accidents like the one he experienced.

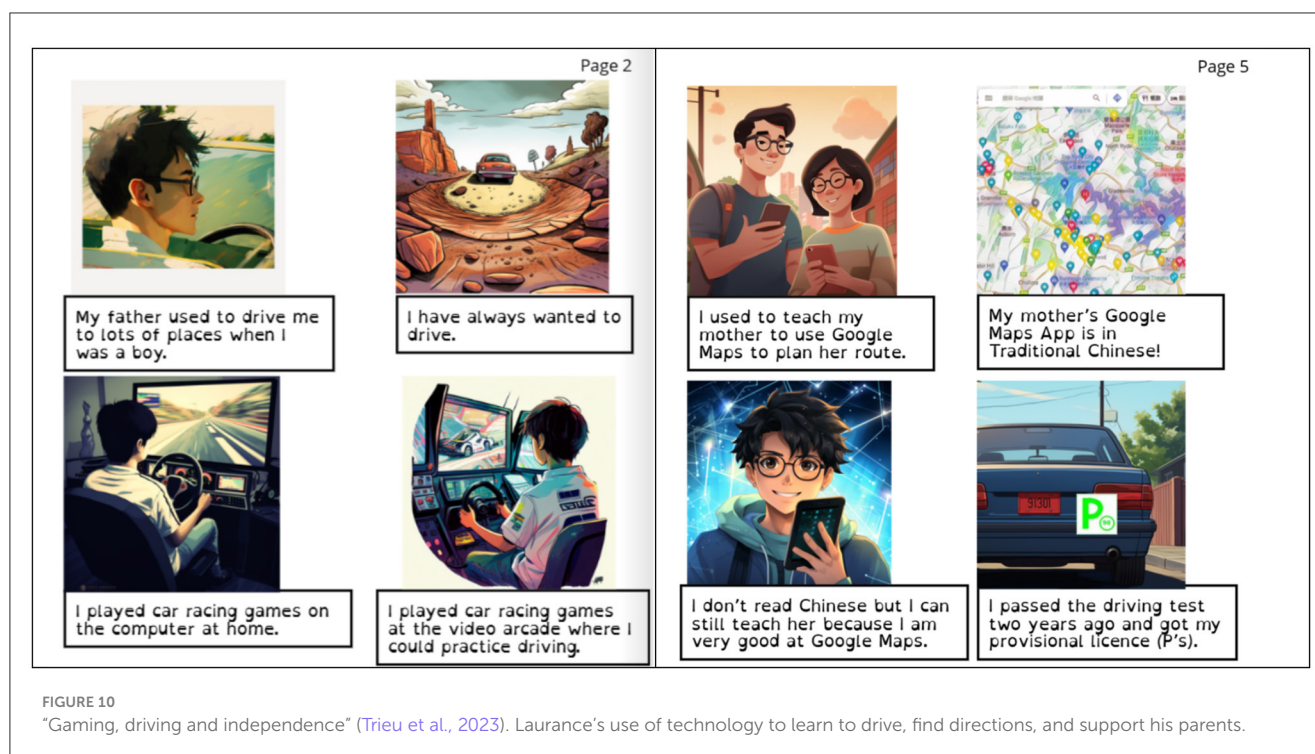
Laurance's gaming interests also played a pivotal role in developing his real-world mobility skills. From an early age, his parents introduced him to a virtual reality driving game with a steering wheel controller, which he used extensively (Figure 10). Over time, this setup provided an accessible and engaging platform for him to develop the necessary skills and confidence in driving. By the time of his e-book's creation, Laurance had successfully passed his driving test and had adopted the role of the primary driver for his aging parents (Figure 10). This marked a significant milestone in his independence and challenged traditional narratives that position individuals with disabilities solely as care recipients. Instead, his story highlights the transformative role of everyday consumer technology in fostering mobility, independence, and the redistribution of caregiving responsibilities within families (Soldatic et al., under review).¹

Taken together, the experiences of Mani and Laurance illustrate the way in which migrants with disabilities actively shape their engagement with everyday consumer technologies, challenging dominant narratives that portray them as passive users. Their stories highlight the critical role of digital agency where individuals not only adapt to technology but also leverage it to assert independence, navigate language barriers, and facilitate caregiving roles. Furthermore, their narratives reinforce the need for an intersectionality-informed, agency-based approach in understanding technology use and recognize that accessibility is not simply about providing technological tools but ensuring that these tools reflect the diverse realities and needs of their users. Through self-directed learning, and the redistribution of caregiving responsibilities, Mani and Laurance exemplify how CaLD migrants with disabilities are active agents in its use, transformation, and integration into daily life.

4 Discussion

Based on the lessons learned through the participatory and intersectionality-informed ADDEPT project, we propose several

1 Soldatic, K., Lee, M., Coe, G., and Magee, L. (under review). Agential technologies or agential subjects: Culturally and linguistically diverse (CaLD) migrants with disabilities and their adaptation of everyday consumer technologies. *J. Ethnic Migr. Stud.*



methodological parameters to guide future disability-inclusive, participatory research. While the parameters focus primarily on participatory practice, we encourage researchers to apply them within an intersectionality-informed framework that explicitly attends to how ableism, racism, xenophobia, linguicism, and other systemic barriers shape participants' experiences and engagements.

First, it is important to maintain a careful balance between in-depth participatory engagement and participant burden. While sustained engagement can enrich the research, researchers must continuously monitor and mitigate potential cognitive, creative, and emotional demand on participants. This is particularly important when working with participants who face multiple systemic barriers which may compound the labor required for research participation. In this project, Nidhi's experience demonstrated how individuals with disabilities are often required to advocate for their own accessibility at every stage, even within research that aims to center their voices. Furthermore, as she described, the English-dominant design of many technologies compounds these barriers for CaLd migrants with disabilities, contributing further cognitive and emotional demands.

Second, methodological flexibility is essential to support inclusive and sustained participation. Research designs, timelines, and engagement methods should be adapted responsively to participants' need and contextual constraint. In the ADDEPT project, the shift to online workshops due to COVID-19 required significant restructuring of engagement strategies. Reducing workshop duration, providing alternative modes of participation and maintaining individualized follow-ups were critical in addressing these barriers, ensuring accessibility and sustained involvement in the project.

Third, sustained engagement and trust-building are critical. Developing long-term relationships with participants fosters deeper, more meaningful research outcomes and promotes participant agency and voice particularly for those who experience

intersecting marginalization that may have fostered historical distrust toward researchers and institutions. In the ADDEPT project, sustained engagement and trust-building enabled Nidhi's collaboration over 2 years which helped refine research accessibility strategies and supported Leza's involvement in shaping an authentic representation of Sadie's story in co-created outputs.

Fourth, participant-led identification of accessibility needs and systemic biases should be prioritized. Engaging participants as experts in these areas supports the co-creation of more inclusive knowledge and ensures that research processes and outputs are grounded in lived experiences. In this project, Nidhi, Leza, and Sadie played an active role in identifying and correcting AI-generated image biases, as well as refining prompts to achieve more accurate representation. However, this process placed an undue burden on individuals who were already navigating systemic barriers, underscoring the need to carefully balance participatory engagement with participant burden as discussed in the first parameter.

Fifth, researchers must remain aware of the persistent limitations of accessibility tools. It is important to develop participant-informed, contextually adaptive approaches that address the intersectional needs of diverse users. For example, while assistive features such as screen readers are widely available, their incompatibility across platforms forced participants such as Nidhi to engage in additional adaptation efforts. Furthermore, the English-first design of many accessibility features excluded participants whose primary language was not English, increasing the burden of navigating exclusionary technological design.

Finally, participatory research should center participants' agency and expertise. Moving beyond deficit-based framings, researchers should recognize the value the active roles participants can play in shaping digital environments, advocating for accessibility, and building community capacity. In this project, participants demonstrated significant agency and expertise; Nidhi

as an active speaker on disability access and as a significant informant for the study; Leza by supporting researchers in developing Sadie's story and giving her a voice; Mani by supporting his parents in learning English and teaching them how to use digital technology to do so; and Laurance by providing practical support and mobility assistance to his aging parents.

Taken together, these lessons emphasize the importance of adopting flexible, participant-centered approaches that account for diverse accessibility needs and minimize participant burden. Furthermore, they highlight that long-term, co-created engagement fosters richer insights and more inclusive research processes and outcomes. The day-to-day use of digital technology for CaLD disability communities is diverse, with added barriers and benefits which may not be otherwise experienced outside of this lens. In conducting participatory, co-creation research with participants with disabilities and CaLD identities, digital technologies served not only as a main topic of inquiry and discussion, but also as tools to engage participants, collect data, and synthesize materials for accessible knowledge dissemination. The methods denoted in this paper contribute to the body of embodied participatory and intersectionality-informed approaches to research and highlight the key understandings of technology use in this context.

Data availability statement

The datasets presented in this article are not readily available because they are for project use only.

Ethics statement

The studies involving humans were approved by Western Sydney University Research Ethics Board. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study. Written informed consent was obtained from the individual(s) for the publication of any potentially identifiable images or data included in this article.

Author contributions

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administration, Visualization, Conceptualization, Software, Methodology, Validation, Investigation, Supervision, Data curation. ML: Writing – review & editing. ET: Writing – review & editing. AL: Methodology, Investigation, Writing – original draft, Formal analysis. LM: Investigation, Conceptualization, Funding acquisition, Software, Supervision, Resources, Writing – review & editing.

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Are we truly fighting ableism? Digressions for a complex society

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Ableism, as a pervasive yet often unchallenged structure of oppression, operates across multiple social domains, shaping perceptions of disability and normalcy. This article interrogates the complexities of ableism through an interdisciplinary framework that integrates complexity theory, Queer theory, and critical disability studies, engaging with the works of Michel Foucault and Georges Canguilhem (among others). Rather than treating ableism as a singular form of discrimination, the study examines its intersections with other oppressive systems, including homophobia, medicalization, and epistemic injustice. By analyzing how blindness, schizophrenia, and paraplegia are socially constructed and regulated, this research highlights how biopolitical and necropolitical mechanisms determine which bodies are deemed valuable, productive, or expendable within neoliberal societies. This framework allows for a deeper understanding of how ableism functions both as a means of control and as a determinant of which lives are considered unworthy of care. Furthermore, by engaging with complexity theory, the article challenges reductionist perspectives that frame disability as an individual deficit rather than as an integral part of human diversity. The implications of this analysis extend beyond theoretical discourse, calling for a reconceptualization of diversity that does not merely accommodate disabled individuals within existing structures but actively deconstructs the epistemological and institutional foundations of ableism. This research contributes to psychological and cultural studies by fostering a critical dialogue on how ableism is reproduced in societal narratives, policies, and everyday interactions. By reframing disability as a site of epistemic and existential richness rather than mere impairment, this article tries to advance a more inclusive understanding of human diversity.

KEYWORDS

ableism, Queer (LGBTQ+), complexity, capitalism, diversity and inclusion

1 Introduction

The Cambridge English Dictionary defines ableism as “policies, behaviors, rules, etc. that result in unfair or harmful treatment of disabled people,” as well as “harmful or unfair things that people say, do, or think based on the belief that disabled people are inferior to those without disabilities” (Cambridge University Press and Assessment, 2024).

Such a definition centers on the term “disability,” which the same dictionary describes as “an illness, injury, or condition that makes it difficult for someone to perform certain activities that others can typically do, often in a permanent or long-lasting manner.” In Brazil, ableist practices are criminalized under the “Lei Brasileira de Inclusão da Pessoa com Deficiência” (Brazilian Law for the Inclusion of People with Disabilities, LBI), Law No. 13.146/2015. An important distinction to make is that “ableism” encompasses broader societal beliefs and practices, while the LBI specifically addresses discriminatory acts.

Although this is the terminology commonly used in the field, the word itself (disability) implies an inability or absence of ability. However, are people inherently able

a priori? If disabled, by what standards? Therefore, one may further notice that the terminology used to describe such diverse human conditions reveals that society still fails to prevent inequity, as it labels individuals as simply “disabled” without considering the myriad possibilities of existence that reality can comprise, where different people could flourish once equity is provided. There is a clear contradiction when we claim equity in our relationships, in workspaces, or in our aesthetics, and at the same time define people simply as “not able” (the strict sense of “disability”).

In general, the effects of misusing the word “disabled” and the conceptual contradictions that surround it still extend to norms, practices, and beliefs that marginalize people based on their differences. As we will discuss, society does not provide space for those people given its cultural values and economic paradigms. Would abandoning the word “disabled” confront an entire system of beliefs and practices that make up the contemporary Western world?

Diverse people could be seen as simply different in a complex social system where many human properties that certainly emerged *in nature* are not despised or devalued based on current cultural hegemonic values. “Complex” here is a term adopted in light of its formal and scientific concept: the physical property of a highly informative, integrated, evolutionary, and, who knows, perennial system (Tsallis, 2020). A complex system needs diversity and collectivity, far beyond what we understand as normality and disability. This means a system that thrives on interconnectedness and varied components rather than strict uniformity. Therefore, as we will discuss here, ableism is one of many paths for the collapse of humanity’s future.

Every individual navigates a landscape of limitations and challenges, coupled with unique individual abilities. This essay aims to unpack the misconceptions surrounding the human condition, beginning with the language used to describe it. We will explore the historical roots of current Western thought, informed by positivist and economic paradigms, which are themselves derived from religious frameworks.

2 What is normality and where did it come from?

“Normal” is a cultural construction. In Western culture, normality is a classical construct based on the Greek moral and aesthetic ideal of man-*kalos kai agathos* (Nussbaum, 2011). The modern economic paradigm, in turn, added the concept of functionality to the idea of what is normal, deriving this concept from the skills necessary for the work in a system of production (Foucault, 1973; Garland-Thomson, 1997).

The notion of what constitutes “normal” versus “pathological” has long been central to the framing of disability, often with the latter term being used to justify exclusion, marginalization, and discrimination. As Foucault (1973) demonstrated in *The Birth of the Clinic* (1973), the medical gaze has played a critical role in constructing categories of normality, turning differences into pathologies that can be diagnosed, controlled, and often segregated. In this context, the term “disability” becomes not only a clinical categorization but also a moral and cultural judgment, reflecting broader societal anxieties about deviation from the norm.

2.1 From the origins of Western thinking

The historical development of Western thought has deeply shaped the way societies define ability, productivity, and normality. From the medieval period through to the rise of scientific positivism, Western intellectual traditions have constructed paradigms that associate the human condition with predefined norms of functionality, often dictated by economic and social utility. The lens through which humanity is understood has been heavily influenced by economic imperatives, particularly the demand for productivity. This framework, which prioritizes efficiency, labor capacity, and economic contribution, forms the basis for what is considered “normal,” “functional,” or “able” (Davis, 1995).

The contemporary Western culture is idealist, reductionist, and normative (MacIntyre, 1981; Polanyi, 1944), based on a market economy (Harvey, 2005), and it has competitiveness and capitalism as cardinal values or systemic implications to how society works in the end (Bauman, 2000; Harvey, 2005). In the medieval period, societal norms were often informed by theological and religious doctrines that framed disability and difference within a moral and divine context. This perspective, rooted in Christianity, viewed bodily and mental impairments as manifestations of sin, divine punishment, or a moral failing (Foucault, 2009). While this period did not rely on the concepts of “efficiency” and “productivity” in the modern sense, it did conceptualize individuals as either fulfilling or failing to fulfill societal roles, ultimately determining their place within the social order. It is important to note that alternative accounts of pre-capitalist Europe exist, suggesting that disability did not always equate to social exclusion, and that every person, regardless of their very subjective capabilities, might have had a place in society (Slorach, 2015).

2.2 The rise of scientific and positivist thought

The dawn of modern science in the Enlightenment and the subsequent rise of positivism further entrenched ideas of normativity through a lens of biological determinism. Thinkers like Auguste Comte played pivotal roles in establishing the frameworks by which human beings and their capacities were measured and compared against a set of idealized standards of functionality. As a consequence, scientists have historically reinforced ableism in their practices, such as treating people with disabilities through demeaning and pejorative terms like “idiot,” “imbecile,” “moron” and “retarded” for people with mental disabilities (Da Silva and Hubbard, 2024).

Ultimately, this ideology evolved into the proposition of the pseudoscience of eugenics by Francis Galton in the late 19th century. Based on an oversimplification of ideas from genetics and natural selection, eugenics proposed that, for the common good of society, the reproduction of “well-born” individuals (e.g., healthy, intelligent, productive) should be promoted, and those who were “defective” should be prohibited from reproducing and passing on their impairments to the next generation (Da Silva and Hubbard, 2024). Although later discredited in its overt forms, eugenics had a pervasive influence on Western biomedical sciences and served as inspiration for discriminatory and violent practices, such as the Holocaust itself. Beyond its historical context, eugenic ideologies contain a disturbing contemporary and/or continuous influence, manifesting in the

ongoing institutionalization, forced sterilization, and restricting immigration policies targeting disabled individuals worldwide (e.g., Canada and Australia). Making this ideological stain in humanity, an ongoing issue that needs to be pinpointed (Puar, 2017). Eugenic ideas were especially detrimental to people with disabilities, serving as an allegedly scientific justification for the prejudice and exclusion aimed at those people.

In this context, any deviation from the presumed norm—whether physical or mental—was framed as a deficit. This scientific reductionism paved the way for the categorization and medicalization of human bodies and minds, and for what Foucault (1965) termed the “medical gaze,” which became an essential instrument for both diagnosing and normalizing human existence. In this sense, disability became inherently pathologized: it was defined not by the social or cultural context, but by a deviation from the norms established through these scientific paradigms. As the Enlightenment gave way to industrialization, these pathologized perceptions began to intersect with economic models of productivity and efficiency, which sought to categorize individuals based on their utility within the growing capitalist economies.

Foucault's (2009) broader historical inquiries and observations, particularly in works such as *History of Madness* (2009), further illuminates how mental health itself, became a political category of deviation, constructed through specific societal practices and institutions. He observes that, madness (for example), became an experience to be medicalized and controlled, while also being something subversive to a singular social fabric. This historical process aligns with the currently western tradition of clustering or pathologizing ‘physical disabilities’ as something deviant from a single norm, excluding and labeling people deemed with such a diagnosis, as people who are considerably unproductive. Thus, mental health as a political canvas over how we deal with certain subjectivities in society, can be a substantial conduit for talking about ableism/disability as something inherently political, albeit defined by very specific logics of power and control.

2.3 Capitalism, productivity, and the concept of normality

Marx's (1867) critique of capitalism, particularly in works such as *Das Kapital* (1867 Volume 1), provides a key theoretical framework for understanding how productivity became a defining feature of normality. Marx argued that capitalism reduces human beings to mere commodities whose value is determined by their capacity to produce and contribute to the economy. The emergence of wage labor, where an individual's worth is measured by their ability to produce goods and services, created a binary: those who could work efficiently and continuously were deemed productive and thus normal, while those unable to contribute to this system—whether due to disability, old age, or other factors—were marginalized as abnormal, dependent, or useless.

This economic paradigm of productivity, reinforced by capitalist values, aligns with the modern conception of functional versus non-functional bodies. In a system where value is determined by labor capacity, the disabled body is often seen as a hindrance to the economic machine (Da Silva and Hubbard, 2024). Marx's (1867, Volume 1) notion of alienation in the labor process—where workers

become estranged from the products of their labor and their human potential—is mirrored in the experience of those labeled as disabled, who often find themselves excluded from productive roles within society. This alienation is not only economic but also social, as it reinforces the idea that disability is inherently linked to an inability to contribute to the capitalist system. Other authors, such as Slorach (2015), Chis (2023), Russell (2001), and Malhotra (2002), can properly highlight to us the inter subjectivities surrounding disability as an adjective defined by capitalistic control, as well. These scholars collectively offer a robust critique of the manner in which capitalism structures the understanding and experience of disability. Slorach (2015) offers a political and historical examination of disability, illustrating its entwinement with the production of capitalist conditions. Chis (2023) expands on this by emphasizing the centrality of disablement to capitalist social relation reproduction and how disability is not an inherent feature but is a process of subjectivation based on economic forces. Russell (2001) and Malhotra (2002) build on this by describing the way that disablement functions within the political economy, suggesting that capitalism creates the very conditions upon which disabled people are constructed and disadvantaged, and upon which they are rendered necessary for its operation. Together, their work goes to explaining that disability, in contrast to the view of it as a medical or individual condition, is a socio-economic construction well-established within, and facilitated by, capitalist production and control systems.

3 Who are the “disabled” ones?

3.1 Diversity and its political meaning(s)

Society often disregards conditions like blindness, deafness, and some forms of neurodivergence as mere anomalies, failing to recognize them as integral aspects of human diversity within a complex social fabric. This medicalized perspective, deeply rooted in Enlightenment rationality and biomedical discourse, constructs disability as a deviation from an idealized norm rather than acknowledging it as a legitimate mode of existence (Titchkosky, 2007). However, framing these conditions solely in terms of deficit erases their potential contributions to epistemological, cultural, and relational diversity. Consider, for instance, the way childhood is understood: a four-year-old cannot independently navigate the world in the same way as an adult, yet this dependency is not labeled as pathological. Instead, childhood is seen as a developmental stage with unique capacities, perspectives, and needs (Goodley, 2014). Similarly, blindness or autism should not be reduced to a set of impairments; rather, they should be understood as different ways of being that shape how individuals experience, interpret, and contribute to society.

This shift in perspective is essential for moving beyond the dominant framework of ableism, which often seeks to either correct or accommodate disability rather than reimagining social structures to embrace it. This approach aligns closely with the British Social Model of Disability, which views disability as a consequence of societal barriers rather than individual impairment (UPIAS, 1975; Barnes, 2000; Oliver and Barnes, 2012). For instance, Deaf Culture is not simply the reunion of individuals who cannot hear, but a rich linguistic and cultural tradition centered around sign languages and visual-spatial communication (Bauman and Murray, 2014). Likewise,

neurodivergent ways of thinking—such as those associated with autism or schizophrenia—challenge conventional notions of reality, perception, and creativity, offering alternative modes of understanding the world (Chapman, 2020). The failure to recognize these as valid and valuable forms of diversity mirrors the way other marginalized identities have been historically framed as deviations from a supposed universal standard. For example, The denial of recognition of indigenous knowledge systems and traditional ecological modes of knowing as valid and deserving expressions of diversity is consonant with the history of non-Christian spiritual practices being framed as the aberrations from some putative universal standard of religious orthodoxy (Smith, 1999; Said, 1978), or, the failure to recognize discrete modes of mobility and sensory experience enacted by people with physical disabilities as valid and preferable forms of diversity is mirrored in the way that non-white racial identities have long been framed as deviations from an assumed universal norm of whiteness and, as a consequence, subjected to systemic oppression (Du Bois, 1903; Fanon, 1952; Mills, 1997).

Diversity, as a social construct, is often interpreted as a medium towards celebrating gender, race, sexuality, and disability. However, this celebratory stance can become frivolous once we acknowledge the exclusionary structures beneath the surface. Ableism, in its multifaceted forms, reveals how diversity initiatives frequently reinforce normative assumptions about bodily and cognitive capacities rather than dismantling systemic barriers (Goodley, 2014). Similarly, the intersection of ableism with homophobia showcases how “queerness” (used here as a broad statement) is frequently underpinned by the exclusionary and dichotomous-based argument of normality (McRuer, 2006). This suggests that the conscientious fight against ableism should be adamantly propelled by the recognition that the concept of “diversity” itself is essentially interwoven by a politically unconscious cultural reality which proposes that certain bodies and subjectivities diverge from a certain norm. For example, diversity initiatives in the labor market that focus on “including” disabled individuals only if they can conform to existing productivity norms, thereby reinforcing the “normal-abnormal” duality rather than challenging the structures that create it.

Within a complex society, power operates through a dispersed (though multifaceted) mechanism, meaning that ableism is at the same time culturally constructed and institutionalized. The medical-industrial complex, for example, does not simply oppress disabled individuals through overt discrimination but also through the production of knowledge that reinforces disability as a defect (Titchkosky, 2007). In a similar vein, the educational system opens itself to diversification, only with the condition that ‘certain subjectivities’ adhere to a predetermined behavioral norm (Meekosha and Shuttleworth, 2009).

The regulation of disability within society cannot be fully understood without engaging with Foucault’s (2003) concept of biopolitics, which describes how modern states exercise power by managing life through mechanisms of surveillance, normalization, and institutional control. Biopolitical power not only seeks to gradually eliminate disability but also to regulate it through medicalization and, ultimately, institutional control. This regulatory logic can be evidenced in the lives of paraplegics who are only integrated into society as long as they can go through very specific forms of “treatment,” such as prosthetics or rehabilitation (Garland-Thomson, 2011).

However, biopolitics is also inextricable from necropolitics, a term coined by Mbembe (2003), which extends Foucault’s framework to analyze how power decides which lives are deemed expendable. Necropolitical structures operate not only through overt violence but also through systemic neglect, as seen in how individuals with schizophrenia or severe disabilities are disproportionately institutionalized, subjected to precarious living conditions, or denied access to care under neoliberal regimes of productivity (Puar, 2017). Ableism then works as both a biopolitical power with ideologically made surveillance regarding who is deserving of control and who is not, interwoven by the necropolitical evaluation of neoliberalism at its core, which is directly responsible for the devaluation and exclusion of certain bodies.

3.2 From the normal and the pathological to Queer theory

Western cultural models have long placed individuals who are outside normativized ideals of able-bodiedness into marginal or subordinate positions, thereby reinforcing ableist structures. Queer theory—which is not a settled doctrine but more of a collection of critical lenses—offers a helpful analytical framework to epistemologically critique these structures. Though explicitly engaged with questions of gender and sexuality, Queer theory’s fundamental disruption of normativity and destabilization of identity have meaningful resonance for the analysis of disability.

Critical theory now, particularly Queer-informed theory, increasingly interrogates the notion of the “norm” as a universal or neutral norm. As Butler (1990) made forcefully obvious in *Gender Trouble*, categories of normalcy are socially constructed (performative) and not natural or based on biology. Butler’s performativity theory—originally formulated about gender—can be applied, with caution, to disability studies.

Performativity in Butler’s theory entails the repeated performative instantiation of norms by lived bodily practices. Transposed to disability, this entails that “disability” is not simply a biological reality but a category constituted by discursive, institutional, and cultural performances. It is important to note, though, that this does not mean that people with disabilities are “performing” disability. Instead, the performance is accomplished through social processes that construct and attribute meaning to disability—medical diagnosis, educational labeling, architectural planning, and policy structures, to name a few.

With that being said, a strictly discursive strategy might miss the embodied materiality of experience. It is therefore important to hold in tension the social construction of disability and the lived life of disabled bodies. A nuanced application of Butler’s theory can illuminate how hegemonic discourses determine the parameters for what is considered “normal” or “pathological.” However, the corporeal and affective existence of disability must be taken into account. This intersectional perspective puts the richness of embodied lives, which are often made invisible by ableist norms and power, front and center.

Rubin’s (1984) seminal essay “The Traffic in Women” offers another lens through which we can understand the intersection of disability and normativity. Rubin examines how sexual hierarchies and gender norms are intertwined with social systems of control, including those that manage bodies deemed deviant or non-normative. While Rubin’s focus is primarily on sexual politics, her analysis is also

relevant to disability studies because it highlights how bodies are regulated and categorized. Just as certain sexualities are pathologized or stigmatized, so too are certain bodies marked as disabled. Both are part of a larger system of societal regulation that positions them outside the realm of “normal” human experience, reinforcing power dynamics that serve to exclude and devalue these groups.

From a Queer Theory perspective, the category of disability is similarly fluid and contingent. Just as Queer Theory challenges the heteronormative binary of male/female, Queer Disability Studies pushes against the ableist binary of able/disabled. Scholars like [McRuer \(2006\)](#) argue that able-bodiedness itself functions as a kind of normativity, structured similarly to heteronormativity, where individuals who embody the “norm” are considered fully human, while those who do not are marginalized or even erased. McRuer’s concept of “compulsory able-bodiedness” mirrors the work of Queer theorists who have exposed how normative heterosexuality shapes and limits our social possibilities ([Butler, 1990](#)). The performance of bodily norms, whether gendered or able-bodied, becomes a site of regulation and restriction, reinforcing the marginalization of those who resist these norms.

To decouple the concepts of normality and pathology from their historically entrenched meanings is to imagine new ways of being and relating that are not confined to binary distinctions. Queer Theory’s focus on fluidity, non-normativity, and resistance to fixed identities offers a framework for rethinking disability. Rather than pathologizing diverse bodies and minds, Queer Theory invites us to embrace the multiplicity of human experiences, rejecting the assumption that there is a singular, ideal way to be human. By using a Queer lens to analyze disability, we can better understand the dynamic, evolving nature of the human condition and the potential for creating more inclusive, equitable societies that honor difference rather than marginalizing it. “Everyone has a part of their life that causes them shame, that they do not show to others, and that affects their way of relating to others. The closet is a place of nonexistence, a place where life can be seen but cannot be touched” ([Portero, 2024](#)).

3.3 Ableism and the neoliberal productivity paradigm

From industrialization and throughout capitalism, with its basis on the notions of individualism and productivity, discrimination and exclusion of those deemed not fit for the system have been the norm, especially people with disabilities ([Mannor and Needham, 2024](#)). In the late 20th and early 21st centuries, the dominance of neoliberal economic frameworks further entrenched this understanding of normality and ability. Neoliberalism, with its emphasis on individualism, market-driven policies, and the devaluation of the social safety net, has exacerbated the marginalization of diverse individuals. Neoliberal thought, which prizes personal autonomy and self-sufficiency, often equates productivity with value. Within this framework, individuals with disabilities are frequently cast as economically nonviable and, therefore, deviant from the normative ideal of a productive, autonomous citizen ([Rose, 1999](#)).

It is a particularly difficult task to harmonize our culture with humanist values regarding diversity (if possible). Moving away from a neoliberal approach that partially includes only worthy/working people with disabilities while also disrupting other ableist

representations of disability requires going beyond including more people with disabilities within the exploitative and individualized social relations of neoliberalism. That is, challenging the contemporary biopolitics of “disability” requires more than access to education, employment, or social lives, but rather requires changing the conditions, practices, and discourses that surround and produce social disability ([Fritsch, 2015](#)). Real transformation demands a fundamental shift, and this includes revolutionizing how we imagine and create our subjectivities.

3.4 A Brazilian legal framework

In the Brazilian context, the *Lei Brasileira de Inclusão* (LBI) represents a groundbreaking legal instrument that criminalizes disability-based discrimination, ensuring the possibility at least, for a broadened and healthy public space for people diagnosed with any disability. However, empirical studies point to substantial political gaps. For example, in schools (private or public), there is a lack of proper staff to attend to children diagnosed with a ‘disability,’ resulting in a significant number of kids dropping out of school early on. As [Nogueira and Santos \(2022\)](#) argue, the LBI is undermined by the ongoing political structures that neglect or deconstruct the material reality of such inequalities in our society. This disparity highlights the importance of analyzing this issue not only on theoretical grounds, but also considering the political practices of the Brazilian society, which is absorbed by colonial problems and structural inequality.

Brazilian scholarship provides a critical framework to conceptualize ableism independently of borrowed theoretical schemes, frequently linking it to past and present socio-economic inequalities. For instance, researchers like [Fritsch \(2015\)](#) examine the neoliberal biopolitics of disability in Brazil to show how commodification of life and labor under neoliberalism plays an important role in determining who gets to be “able” and who is left out, and in the process, they discover that inclusion strictly depends on being productive and independent. Furthermore, evidence from scholars such as [Meekosha \(2011\)](#), even though from a general decolonial perspective, strongly echoes the Brazilian situation by emphasizing how ableist architectures that are reproduced by colonial legacies shape public policies and social opinion regarding disability. This decolonial critical vision, shared widely in the broader Latin American disability studies, argues that ableism is inherently bound to intersectional oppressions like race, class, and gender and necessitates localized analyses sensitive to the concrete structural and historical injustices of the Global South.

4 Complexity and diversity intertwined

4.1 What makes up complexity?

In the contemporary discourse on diversity, the concept of complexity plays a pivotal role in understanding the intricate tapestry of human experiences. In Physics, complex systems—whether social, biological, or ecological—are not merely the sum of their parts but are characterized by interdependencies, nonlinear relationships, and emergent properties ([Miller and Page, 2007](#)).

Morin (2017) synthetically presents to us the possibility of understanding “complexity”: “that which is woven together.” Complexity, far from being a quality of Nature, is nowadays a new epistemology of human reason, set alongside classical, Cartesian, and positivist scientific thought: a large part of the world is only intelligible in terms of complex thinking.

We identify a complex system wherein we observe a group of diverse individuals (individual diversity) that are indeterminate (in chaotic configurations, states, and behavior) from which, surprisingly, collective organization processes emerge, without central control or *a priori* design. Self-organization at an order level above individuals is possible because the fact is that these individuals are also intrinsically related or connected to each other. Diversity promotes greater possibilities for the emergence of new states. And connectivity/correlation allows for the resonance and amplification of local change to the global level. Thus, in a paraphrase of Morin, complexity is the activity of diverse actors who co-create multiple possible common realities.

A universe devoid of diversity would be compared to a crystal, where every individual is exactly replicated to form a monotonous macro-structure and which is incapable of evolving. In the absence of diversity, there can be no emergence of novelty (even from the physical point of view!), no self-organization. There would be no life and its evolution arising in a pluripotent universe made up of billions of species, no human mind, and not even society.

By extension, complex thinking assumes the characteristics of complexity. Complex thinking enables plurality within a logic where “AND” takes the place of “OR,” where dichotomy and monovalence are the exceptions instead of the rules. In systematizing old reductionist scientific thinking, we brought ancient medieval moral teachings into modernity. Previously, something was right or wrong for purely moral and metaphysical reasons; now we decide something as right or wrong for scientific reasons, by the logic of reductionist thinking. Reductionist scientific thought has solved countless problems and brought unimaginable technological advancements four centuries. But answers to ancestral questions such as “what is life” or even “who are we” lie outside of normal scientific thought. Our culture imposed a secular life. So Western man thinks in a way incongruent with the reality of the world. The complexity science today proves that non-complex processes are the exception instead of the rule (Tsallis, 2023; Gell-Mann and Tsallis, 2004), so the Universe, from astrophysics to cultural evolution, evolves under the paradigm of complexity.

Far beyond physics and Biology (Maturana and Varela, 1987; Capra, 1996), Philosophy, through Spinoza’s Ethics and his theory of affects (Peixoto, 2016), as well as the works of Morin (2017), has presented complexity as an interdisciplinary paradigm.

4.2 What can be said about ableism through the lens of the complexity paradigm?

The works of Morin (2017) have been leading philosophical inquiries into the field of complex thought and its implications, contributing significantly to the creation and consolidation of the complexity paradigm. Morin’s theory understands complexity not as an answer, but as a challenge for our worldview and knowledge. It conceives complexity as composed by principles, some of which

we can highlight and use as tools to shed light onto the problems concerning ableism in an attempt to explore and propose new insights. Such an approach is in line with Morin’s view of the complexity paradigm as having its essence in the tendency to build relations.

The recursive principle states that a core trait of complexity is the capacity of a being to create the conditions for its existence—autocausation. Recursion is a defining characteristic of living beings (Maturana and Varela, 1987), but is also observed in cultures and cultural practices. For example, the discrimination that people labeled as disabled suffer plays an important role in keeping those people away from socially valued spaces—education, work, media, etc.—, reinforcing ideas of them being incapable of occupying those spaces due to the resulting lack of representation, ultimately creating a feedback on discrimination itself. Accordingly, labeling those people as disabled reproduces the idea that there is a norm—being able—from which some people diverge, which keeps this idea alive. There may be many other examples of ways through which ableism maintains itself, but the fact is that the only way to stop its recursion is to block the feedback cycle—for example, opposing the use of discriminatory language.

The dialogic principle states the urge for dialogue between different ideas and people for the establishment of complexity. As such, the complexity paradigm embraces the employment of fuzzy logic; thus, different propositions are not seen as inevitably opposing or mutually exclusive, but as possibly connected and complementary. We propose ableism as a product of a worldview that lacks complexity and, therefore, dialogue. It is characteristic of a simplistic way of thought to try and reduce, disjoin, and oversimplify complex concepts as an attempt to better understand them, but the consequence of this approach is often the opposite, leading to a poor and reductionist view (Morin, 2008).

Contrary to the principles of the complexity paradigm, ableism poses itself as a conditioning principle; that is, a principle that conditions (limits and regulates) thought, hindering people from perceiving things that are outside its scope. As such, ableism as a conditioning principle produces simplified and reductionist ideas about human existence, limiting the concept of being human to a bundle of capacities and dehumanizing those who do not fulfill them (Reynolds, 2021). Human existence is singular and varied simultaneously. Capacities are part of what people are, but people are more than the sum of their parts. However, only a way of thinking that comprises complexity can dialogue with ideas like that without the need to simplify them (Morin, 2008).

We propose a dialogue between the ideas of ableness and disableness, as they do not exist in absolute. No one is able or disabled in everything. Indeed, every person encompasses both abilities and disabilities in them, interwoven in complex ways that make every person unique. In fact, some people deemed as disabled might even report valuable aspects of the condition they experience—the case of people with attention deficit hyperactivity, which is considered a mental disorder (and, therefore, inherently a lack of functionality), although a majority of those people report positive characteristics of having the condition (Schippers et al., 2022).

In other words, ability is a concept that is difficult to define with clear and precise borders. Therefore, we propose that ability and disability should be seen as a continuum that is constructed amongst the social environment and is a characteristic of humanity as a whole, not an aspect of some “disabled” individuals. This does not imply

making people with disabilities and their daily struggles invisible. On the contrary, it is about showing that their struggles derive from beliefs and practices of a society that is *unable to include* them, not inherently from their differences. This shift from the notion of disability as an individual trait to the comprehension of it as a contextual factor that emerges from the interaction between the individual and the physical and social environment is fundamental for a more complex and effective confrontation of ableism (Reynolds, 2021).

4.3 What is a complex world made with diverse people?

The political, cultural, and economic understanding of the problem of ableism and the importance of human diversity for a prosperous and healthy society needs to undergo the paradigm of complexity. Thus, this perspective invites us to reconsider the traditional binary classifications that often underpin ableist narratives, framing disability as a deficit rather than a unique facet of human diversity. Diversity in humanity, in its broadest sense, encompasses variations in race, ethnicity, gender, age, sexual orientation, and ability, reflecting the multifaceted nature of human existence (Rosenblum and Travis, 2000). Acknowledging this diversity requires an understanding that each individual possesses a unique set of strengths and challenges, shaped by an interplay of personal, social, and environmental factors.

Moreover, a complex worldview challenges the prevailing paradigms of reductionism often found in Western thought. Reductionism, which seeks to understand phenomena by breaking them down into their constituent parts, can obscure the holistic nature of the world, particularly the human conditions (Capra, 1996). As Canguilhem (2008) argues, the norm should not be viewed as an absolute standard; rather, it is essential to recognize the dynamic interactions that define health and illness.

5 Discussion

In exploring the intersections of ableism, normativity, and diversity, this essay has examined how societal frameworks of normality have historically marginalized those who deviate from the idealized “able-bodied” and “productive” standards. Drawing on the insights of diverse theories, it becomes evident that human diversity—whether in terms of race, gender, ability, or other social categories—is not a mere additive quality, but an emergent property of dynamic, independent systems. This holistic view challenges the reductionist paradigms that have dominated Western thought since the medieval period and continue to shape our understanding of diversity as disability. As Canguilhem (2008) and Foucault (2006) suggest, the distinction between the normal and the pathological is socially constructed and serves as a tool for regulating bodies and behaviors by societal needs, often in ways that marginalize those who fail to conform.

The historical shift from medieval religious doctrines to scientific positivism, coupled with the rise of capitalist and neoliberal economic frameworks, has entrenched the valorization of productivity and efficiency, further solidifying ableism as a central axis of social exclusion. As Marx (1867) and Fritsch (2015) have

shown, the commodification of human labor in capitalist societies has rendered non-productive bodies—whether disabled, elderly, or otherwise outside the economic machine—as disposable or inferior. The neoliberal model exacerbates this by framing individuals with disabilities as liabilities, measuring their worth through a lens of economic viability. Thus, the challenge is not merely to provide access to education or employment, but to radically transform the structures and narratives that produce and sustain such exclusionary systems.

Queer Theory, particularly as articulated by Butler (1990) and Rubin (1984), offers a transformative framework for rethinking the categories of normality and pathology. By extending the theory of performativity to disability, we can reject the binary logic that constrains both gender and ability. As McRuer (2006) points out, compulsory able-bodiedness mirrors the mechanisms of heteronormativity, both of which function to marginalize those who resist conformity. A Queer lens, therefore, not only illuminates the fluidity and diversity of human experience but also calls for a rejection of fixed identities and the rigid classifications that undergird ableism.

The complexity paradigm is a theoretical tool that enables us to explore new insights into various themes, including ableism and diversity (Morin, 2008). In this paper, we have proposed more complex ways of understanding diversity which go beyond the simple inclusion of people who fall outside of what is considered “normal”; on the contrary, we challenge the normal-abnormal binary by exposing how it is a social construct and analysing how diversity is characteristic of humanity itself, not a particularity of some deviant individuals. Embracing a complex understanding of diversity aligns with principles of intersectionality, which emphasize that identities and experiences are shaped by multiple, overlapping social categories (Crenshaw, 1989). This approach allows for a nuanced exploration of how ableism intersects with other forms of discrimination, revealing that the experience of disability is not monolithic but rather shaped by various factors, including race, gender, and socioeconomic status (Shakespeare, 2006). In this context, the term “diversity” transcends mere representation; it becomes a lens through which we can examine the rich tapestry of human experience that exists beyond conventional norms (Schneider, 2006).

Based on our earlier discussion of pathologization and the construction of normality in the past, it is easy to understand how ableism arises in relation to the social understanding of mental health. Despite significant technological and economic progress, affluent societies manifest out-of-proportion elevated rates of anxiety, depression, and other related mental illness (WHO, 2023). These cultures, typically organized around concepts such as individualism and neoliberal forms of progress and productivity, are thoroughly shaped by the very normalizing gaze Foucault was arguing against. In these cultures, mental distress is often seen as a subjective failure, a ‘disability’ in itself, rather than a potential consequence of pressures of the system to be constantly productive and conform to an ‘able’ standard. This serves to stigmatize the non-completable, ableism being instilled into the very essence of modern life (Abramov and Peixoto, 2022). These situations show that mental distress is not only defined by clinical diagnosis but also by a culturally formed manner of conceptualizing human subjectivity, a sign of a society’s inability to embrace polymorphous forms of existence. In order to overcome ableism, therefore, is to

pay closer attention to how political stances and culturally derived attitudes educate us about the possibilities of the human body both subjectively and objectively.

Ultimately, this paper invites a reimagining of diversity as part of the broader human condition—a diverse and evolving spectrum of lived experiences, rather than an inherently pathological deviation from the norm. An inclusive and diverse society is necessary for a complex and healthy life. Embracing this complexity and the intersectional nature of identities offers the potential for a more equitable society, one where difference is not merely tolerated but celebrated. In dismantling the closets of ableism, we open the possibility for a future where all forms of human existence can be seen, lived, and celebrated. By answering the title of this article with a historically and epistemologically based reflection, we got to recognize how far we have come and how far we still need to go. We must revolutionize our subjectivities for diversity to be the gateway to our future as a society.

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A fight worth remembering: sharing archival materials in interviews to support recall of ex-mental patient activism

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This institutional ethnographic (IE) study of a little-known Ontario-based mad history recounts how, in the 1980s and 1990s, ex-mental patients established a number of social enterprises (also known as consumer/survivor businesses), secured government funding and through these sites, got politically active around issues that impacted their lives. This research poses critical sociological questions about the circulation of activist knowledge-practices and the formation of these businesses as sites of community organizing. Methodologically, IE offers an approach through which I began from the experiences of ex-mental patients while aiming to explore how their activist practices are coordinated trans-locally. By interviewing 42 people who were involved in or supported consumer/survivor businesses and by assembling and digitizing materials from their personal collections, archival collections and the businesses themselves, this work brings into view the central role that consumer/survivor business played in mad people's activism locally. Formulated at the intersection of mad studies, social movement studies, feminist theories and sociology of knowledge, this study drew on IE interviews using archival data in innovative ways. Pointing to concrete examples, I put forward numerous benefits to using archival materials in interviews to aid participants in recalling events from the not-so-recent past. Arguably, engaging archival materials during interviews can enhance accessibility for populations who are older, experience memory issues, have a history of psychiatric interventions, or for anyone who may benefit from material prompts to resituate them to a particular time and space. Looking through materials alongside participants may serve to initiate discussion and prompt recall, evoking participants' memories of past events and the meaning they attribute to these, in turn producing richer stories. Doing so may help to ensure key informants are able to make meaningful contributions to sociological research on histories of activism. Talking to participants about archival material can help researchers to make sense of those materials, their connections and sequencing. Additionally, audio and visual materials may bring the contributions of community members who are no longer with us back into dialogue with those who are.

KEYWORDS

archival research, interviews, qualitative methods, institutional ethnography, mad studies, accessibility, memory, activism

Introduction

What happens when a collective history being researched rarely appears in formal archives, not having been gathered together in a cohesive, orderly collection? Undoubtedly events occurred and the many people sharing in its collective memory can tell its stories and are connected through shared identity, yet this history is largely absent from archival records. Instead, it appears in the scraps of paper, the newspaper clippings, the photo albums in dusty boxes in the basement of the people who took part in it many years ago. What happens when all the primary sources are scattered between precarious lives, jobs and organizations? What then does it mean to gather these dispersed records—documents, videos, photographs, T-shirts, buttons—as part of the research process, so they may be used to articulate collective memories, knowledges and identities?

Further to this, underscoring presumptions of memory as being a place in our mind where recollections of the past are organized in a coherent, linear fashion, what happens when this collective history is an activist history of groups of mad people? How might interview methods be made accessible when research participants experience recall barriers linked to age and iatrogenic harm¹ from a lifetime of psychiatric interventions? How might archival materials be used to engage people who share in this history and knowledge, through the interview process?

Millar (2006) emphasizes the importance of archival materials “as evidence, as memory triggers, as touchstones” (125) which are socially mediated and contribute to the development of collective knowledges and identities. Though much more than simply prompts, archival materials can provide important memory cues to elicit recollections, whether those are semantic memories (those that affirm that an event took place), or for individuals who were present at the event depicted in the materials, episodic (remembrance of personally experienced events) or sensory memories. In this way, archives can be tools “used to support the creation, preservation, and resurrection of individual memories and, more importantly, their articulation as part of a shared identity” (2006:126).

This article outlines one institutional ethnographic (IE) study where archival materials—largely gathered from personal and business collections—were introduced and discussed during semi-structured interviews. Six benefits of using a range of archival materials within interviews, to aid participants in recalling events from the not-so-recent past, are put forward. First, introducing archival material in interviews facilitated the gathering together of additional materials. Participants directed me to locate documents corresponding to the stories they told, or they offered to share additional materials from their own personal or business collections.

Many of these materials would otherwise never have been shared publicly or preserved digitally. When consent is given to share these materials publicly, the multimedia formats of archival records offer many possibilities for knowledge translation and mobilization, nurturing new forms of public sociology. Second, engaging archival materials during interviews may enhance accessibility for research populations who are older, experience memory issues, have a history of psychiatric interventions, or for anyone who may benefit from material prompts to resituate them to a particular time and space. Doing so aims to ensure key informants are able to make meaningful contributions to sociological research on histories of activism that are not well documented in formal archives. Third, looking through materials alongside participants may serve to initiate discussion and prompt recall, evoking participants’ memories of past events and the meaning they attributed to these. Fourth, it can improve responses to produce richer stories and in the case of institutional ethnographic studies, further develop the mapping of social relations. Fifth, looking through materials from personal collections with participants can help the researcher to make sense of those materials, their connections and sequencing. Sixth, audio and visual materials may also bring the contributions of community members who are no longer with us back into dialogue with those who are.

Object-oriented interview studies have also identified a range of benefits to asking interview participants to engage with “mundane things that make up our everyday lives.” For instance, Owen et al. (2021) indicate that object-oriented interviewing can: provide insight into an individual’s life course, improve autonomy for participants in deciding how the conversation will flow, help participants to untangle complex developments in their lives, aide them to speak openly with emotions and from memory to a greater depth, provide larger quantities of data and lastly, provide cathartic opportunities for the participant to reflect. Harrison et al. (2024) add that objects can become dynamic actors in interviews, materializing the events, accounts and experiences of participants as well as materializing their practices. Objects can also serve as “spatiotemporal ‘anchors’” by situating the interview in relation to other places and times, past, present and future (p. 397). Additionally, Harrison et al. (2024) emphasize that digital objects (i.e., photos, songs) can provide insight into the evolving nature of objects and the meanings people assign to them.

Primarily, this article focuses on interview methods, specifically the practice of engaging archival materials within the interview process, arguing that qualitative interviews outside of the oral history or life story genre could also benefit from bringing archival materials from personal collections and activist ephemera into the interview process. A secondary aim is asserting the early history of consumer/survivor businesses in Ontario as sites of community organizing. By way of an outline, this article began by posing questions of memory and archives, to put forth the idea that archival materials may be beneficial tools to aid in qualitative interviews. Next, the emergence of consumer/survivor initiatives (CSIs) including consumer/survivor businesses in Ontario, Canada will be situated in their historical and political economic context, establishing their link to community organizing, advocacy and activism by current and former mental patients. In the section, ‘Materials and Methods,’ the literature on object-based interviewing in the oral history tradition is introduced. I describe how a creative application of Smith’s (2005) institutional ethnography (IE) during the pandemic forms the methodological

¹ By iatrogenic harm, I refer to the range of injuries and harms that can result from psychiatric interventions. These can range from physical and psychological injuries to an erosion of trust in medical professions. Iatrogenic harms may include, but are not limited to, memory loss caused by Electro-Convulsive Therapy (ECT), Post-Traumatic Stress Disorder (PTSD) from pharmaceutical and non-pharmaceutical interventions (i.e., physical or chemical restraint use), and harms that are a by-product of being denied care or receiving poor care from healthcare providers. For more on iatrogenic harm, see: Kaissieh (2023) and Johansson-Everyday (2023).

basis of this research. I account for the materiality of the archival records acquired through this study, consider the relational ethics of engaging these materials with care and reciprocity, and story one example of how materials were gathered through the interview process. In 'Results,' I provide three concrete examples of how materials were shared or paired within interviews and to what effect. The final 'Discussion' section aims to contribute to the literature on sociological research methods by discussing the wider potential application of this method, to better engage with and meet the needs of a range of populations, including but beyond people with mental health histories and older people. I end by reflecting on the impetus to preserve and digitize local material histories of mad activism, particularly in recognition that these material histories and organizations are at risk of being lost.

Context

In the 1980s, a few groups of current and former mental patients in Ontario were successful in establishing small businesses akin to social enterprises, or what came to be known as consumer/survivor² businesses. Some of these early businesses included: The Mad Market (established 1980 in Toronto), ABEL Enterprises (established 1983 in Simcoe), A-WAY Express (established 1987 in Toronto) and Fresh Start Cleaning and Maintenance (established 1989 in Toronto)—the last three of which are still in operation in 2025.

Ontario's political and economic context was shifting dramatically at the beginning of the 1990s. Canada was experiencing a deep recession from 1990 to 1992, followed by high rates of unemployment. The period from the late 1980s to early 1990s marked a significant shift in mental health policy in Ontario (Nelson et al., 2001). To the surprise of many, in 1990 a leftist New Democratic Party (NDP) provincial government took power for the first time in Ontario's history. This incoming government had a newfound appreciation for consumer participation³ in mental health. Survivor-led alternatives to the mainstream mental health system, such as peer support organizations and drop-ins, had been cropping up across the province in the 1980s, mostly operating on shoestring budgets. In addition to advocacy by consumer/survivors, throughout the 1980s, organizations such as the Canadian Mental Health Association (CMHA) National had been

working to develop the policy groundwork to support consumer participation (see: Church and Trainor, 1986) and the Graham report in 1988 (Provincial Community Mental Health Committee, 1988) signalled a significant shift to future investment in community-focused mental health services. Then in 1991, Ontario announced \$3.1 million in anti-recessionary funding for the Community Mental Health Branch of the Ministry of Health. The branch used the funds to establish the Consumer Survivor Development Initiative (CSDI), now known as Peer Works, citing recent policy recommendations including the Graham Report. CSDI would go on to fund consumer survivor initiatives (CSIs) such as peer-support groups, but also consumer/survivor businesses. From the initial call for proposals, 42 CSIs were selected from 250 applicants to receive provincial funding through the Ministry of Health. The successful CSIs covered all regions of the province, becoming formally recognized as part of the mental health sector in Ontario (O'Hagan et al., 2009).

The Consumer Survivor Development Initiative came about during a time of significant change in the consumer/survivor/ex-patient (c/s/x) movement. More commonly referred to now as the 'mad movement,' the consumer/survivor/ex-patient (c/s/x) movement emerged during the late 1960s and early 1970s as a loosely organized social movement led by ex-mental patients (Everett, 2000; Morrison, 2005; Reaume, 2021). What began as a decentralized grassroots movement across the Global North, is now international in scope but remains fragmented and loosely coordinated (Logan and Karter, 2022; Morrison, 2005). In the 1990s in Ontario, the c/s/x movement—then in its 'consumer' phase—was more reformist and entrepreneurial than earlier movement organizing, adapting to the recession and later, to a conservative provincial government (1995–2003). Adopting new language that reflected an engagement with (rather than strict opposition to) the mental health system, consumers pulled away from more radical organizing, shifting to more service-oriented approaches. Little research has been done on this less radical 'consumer' phase of the c/s/x movement or the unique organizational form of the CSI, despite CSIs being hugely innovative, highly effective, and cost-efficient (Shute, 2021).

The study at the center of this article focuses on the advocacy, activism and community organizing which took place within consumer/survivor businesses from 1980 to 2005 in southwestern Ontario. Arguably, despite less radical inclinations during the 'consumer' phase of the c/s/x movement, substantial covert and overt forms of advocacy led by consumer/survivors were cultivated within CSIs, including consumer/survivor businesses during this period. Consumer/survivor businesses are small and similar to social enterprises; they operate primarily, though not exclusively in the service sector. A large number of these current and former businesses operate in and around the Greater Toronto Area (GTA), as outlined in Table 1. Though some consumer/survivor initiatives were intentional about documenting their activities, consumer/survivor advocacy has generally not been preserved in conventional archives or databases. Some exceptions to this include the Psychiatric Survivor Archives of Toronto⁴ and a few fonds with the Toronto Metropolitan University Archives.

² Consumer/survivor refers to self-identifiers of (mental health service) 'consumer' and 'psychiatric survivors'; the blended term indicates all people who either use or refuse mental health services. The language of 'consumer/survivor' is used throughout the article as it reflects the self-identifiers embraced at that time and place by research participants and their organizations.

³ By consumer participation, I am embracing the wide range of similar terms (consumer involvement, patient engagement, etc.). Consumer/survivors had to that point been excluded from representing themselves in mental health policy, research and service provision and were advocating for their right to have input into in these arenas. The term 'consumer' emerged out of mental health policy changes in the 1980s and 1990s that redefined ex-mental patients as 'consumers' to legitimate their involvement, denoting respect by equating them with customers. Psychiatric survivor, on the other hand, was a self-identifier created by ex-mental patients themselves, drawing attention to harms caused by the mental health system (for more, see: Everett, 2000).

⁴ The Psychiatric Survivor Archives of Toronto is not currently accessible to the public. The board is currently rebuilding.

TABLE 1 Consumer/survivor businesses in Ontario.

	Consumer/Survivor business	Sector	Location
1.	ABEL Enterprises	Woodworking	Norfolk county/Simcoe
2.	A-Way Express	Courier service	Toronto
3.	Cambridge Active Self Help (C. A. S. H.)	Ceramics	Cambridge
4.	Clerical Express	Secretarial	Kitchener
5.	Crazy Cooks Catering*	Food services	Peterborough
6.	C/S Lawn Care	Landscaping	Etobicoke
7.	Daisy Café	Food services	Windsor
8.	Fresh Start Cleaning and Maintenance	Cleaning	Toronto
9.	Garden Delight Juice Bar	Food services	Windsor
10.	The Grill*	Food services	Toronto, on-site at CAMH
11.	Innovative Enterprises	Social enterprise development	St. Catharines
12.	Inspirations Studio (previously Inspirations Women's Collective)** and Ideas Work Studio	Arts and crafts	Toronto
13.	The Mad Market	Consignment	Toronto
14.	New Look Cleaning	Cleaning	Etobicoke
15.	Our Place	Arts and crafts	Norfolk county/Simcoe
16.	Out of this World Café*	Food services	Toronto, on-site at CAMH
17.	ParcArt	Arts and crafts	Toronto
18.	Parkdale Green-Thumb Enterprises*	Landscaping	Toronto
19.	Prezents of Mind	Arts and crafts	Toronto
20.	Quick Bite Catering and Take-Out	Food services	Brantford
21.	Raging Spoon*	Food services	Toronto
22.	Rainbow Ceramics and Crafts	Arts and Crafts	Hamilton
23.	RecyCLEAN	Cleaning	Oshawa
24.	Ten Friends Diner	Food services	Windsor
25.	Wise Choice Café	Food services	Barrie

The 8 businesses indicated in bold remain in operation in 2025. *Working for Change, previously the Ontario Council of Alternative Businesses (OCAB) and prior to that the Consumer Survivor Business Council, is an umbrella organization which operates these businesses solely or in partnership with other organizations, as well as leadership and training programs. See: workingforchange.ca. **Initially established by a CSI as a craft collective for under-housed women, Inspirations Studio now operates as a storefront ceramic studio for women and gender diverse people who experience poverty, marginalization, homelessness or mental health issues.

Though “social enterprises exist on a spectrum” (Ali, 2017), the ‘by and for model’ (Corbière et al., 2019) of consumer/survivor business makes them quite distinct from earlier models of vocational rehabilitation, sheltered workshops and other forms of psychiatric service provider-led programming. This is primarily due to their grassroots origins, egalitarian approach, compensation for workers, and being survivor-led at all levels of the organization. Secure government funding marks consumer/survivor businesses as unique to Ontario and makes it possible to offer a limited number of consumer/survivors much needed accessible job opportunities. This funding structure afforded consumer/survivor businesses the opportunity to fully establish themselves and through these sites, many consumer/survivors found community and got politically active around shared issues that impacted their lives. Arguably, this funding would have the unintended effect of structuring the possibilities for local consumer/survivor/ex-patient movement activities throughout this time period.

There was significant overlap between the aims of c/s/x movement in Ontario and what CSIs including c/s businesses were advocating for

because movement leaders often doubled as leaders of these organizations, which in turn became sites where advocacy was incubated. As described by one interview participant, Jennifer Chambers, CSI leaders “were the most visible part of the movement in Ontario” during that time. At their early stages, consumer/survivor businesses were a means to an end for c/s/x organizers. Survivor leaders who took it upon themselves to manage and lead these businesses, such as the late Diana Capponi, were in fact “in the business of changing lives” (Church, 2020). Few survivor business leaders held business, managerial or finance backgrounds which might be more common amongst other forms of social enterprise. In a presentation to the Ontario Association of Social Workers, Dr. Tanya Shute, a past executive director of the Krasman Centre (a CSI peer support drop-in based in Richmond Hill, Ontario), referred to CSIs (of which consumer/survivor businesses are a part) as “born of a movement and accountable to that movement” (Shute, 2021).

There is more to consumer/survivor businesses than their therapeutic potential, or their ability to put a few dollars in community members’ pockets. While these are important aspects, they overlook

what motivated establishing consumer/survivor businesses. While CSIs have changed over time, interview participants narrated them as having resistant, even disruptive origins. Having a base of operations during a recessionary period was a valuable resource which survivor leaders could leverage to rally community members and organize around pressing issues facing their community. For example, the Raging Spoon restaurant⁵, a consumer/survivor business with a large space often used for c/s/x community gatherings, once hosted an event where the Parliamentary Assistant to the Ontario Minister of Health, Dan Newman, was invited to hear directly from consumer/survivors about what they felt needed to change in the mental health system.⁶ Hosting the event in a space that was accessible to consumer/survivors, allowed over one hundred community members to attend and participate in the Ministry's stakeholder consultation.

In the broader literature on social firms or social enterprises for disabled people, generally stated, research questions tend to focus on vocational outcomes, accommodations for workers, employment retention and/or job satisfaction. In the last decade, only a handful of studies on consumer/survivor businesses have been published (Buhariwala et al., 2015; Corbière et al., 2019; Hall and Wilton, 2011; Krupa et al., 2019). None of these recent studies lays out the formation of these businesses as an explicitly activist intervention and site of community organizing. Going back further, over the last three decades there have only been a dozen or so more studies of consumer/survivor businesses (Church, 1996, 1997, 2001; Church and Creal, 1995; Hartl, 1992; Krupa, 1998; Parkes et al., 2002; Shragge and Church, 1998; Trainor et al., 1997; Trainor and Tremblay, 1992). These early studies were more often written up by researchers with some direct connection to consumer/survivor businesses and were more likely to acknowledge advocacy as a trademark of this organizational form. I argue that consumer/survivor businesses in Ontario were sociologically significant sites of community organizing and to miss this point in the recent literature on consumer/survivor businesses is to misunderstand their purpose. Studying the formation of this unique organizational form, particularly in those early years (1980–2005) when advocacy flourished, offers a deeper understanding of how consumer/survivor advocacy was socially organized. In what follows, I introduce this study's methodology, institutional ethnography, and methods of conducting semi-structured IE interviews, gathering archival materials, and bringing some of these materials into the interview process.

Materials and methods

Within the fields of oral history and life story or life history research, there are established practices of bringing material objects into

the interview process (Plummer, 2001). Object based interviewing, or object-oriented research has been used to study material cultures in family relations and household spaces, often through the use of photographs, personal or domestic items (see, for instance: de Cardoso Sousa, 2021; Green and Luscombe, 2019; Hall, 2019; Wilton, 2008, 2015). Personal possessions have also been incorporated into oral history studies of migration narratives (Cosmini et al., 2018) and in studies of diasporic identities (Ajit, 2015). In object-based interviewing, interviews are sometimes led primarily through a focus on an object itself (Ravn 2022), though some proponents argue for an approach that does not make the object itself the dominant focus (see, for instance: Wilton, 2008). Creative research activities may also be engaged as part of object-based interviewing, such as: freewriting, close looking, collage, line-drawing or mapping (Bates and Fleetwood-Smith, 2025). Reichard's (2012) study of queer campus activism in 1970s America brought activist ephemera into oral history interviews, which he argues are well-positioned to both aid participants in recalling events and as a producer of content (ephemera revealed through oral history). The meaning of the student-produced ephemera in Reichard's study was enhanced through oral history, by "capturing the 'self-understanding' of those who created it" (2012, p.54) and contributing those self-understandings to the creation of collective memories of queer activism. Reichard's study highlights the need to preserve and make sense of activist ephemera, particularly amongst marginalized communities whose contributions are not well represented in 'official' records.

This article, based on my doctoral research,⁷ is informed by the work of sociologist Dorothy Smith. Smith's (1978, 1990) and David and Smith (1975) early theorizing was heavily influenced by the women's movement and to a lesser extent, ex-mental patient organizing. Smith's *'K is Mentally Ill'* (1978) and *The Conceptual Practices of Power: A feminist sociology of knowledge* (1990) stand out as testament to feminist theorising that challenged core sociological tenets, namely how objectified forms of knowledge get used to oppress women. In *The Conceptual Practices of Power*, Smith draws from her own experiences of psychiatrization ('Introduction', 1990) to brazenly challenge the fundamental tenets of psychiatry. Smith's work stands as feminist sociological cannon with respect to madness, pushing back against women's psychiatric oppression. Through statistical and text-based analyses, Smith demonstrates to researchers how we might flip the questions that we ask and pay attention to psychiatric practices in order to understand how ruling relations determine women's experiences as psychiatric patients. Smith's early publications (1975; 1978) made bold arguments for understanding women's experiences of the psychiatric system as a political issue.

The methodological framing of this study follows Smith's institutional ethnography (IE). A historical materialist approach positioned as an alternative sociology "for people" (Smith and Griffith, 2022), or as a method of inquiry, IE starts from research subjects' every day/night lives and extends beyond that experience as it aims to discover the social. The social can be located in how people's practices are coordinated trans-locally with the doings of others. Research subjects are not objectified in the process; rather standpoints serve as entry points for

⁵ For a number of years, the Raging Spoon operated a bricks and mortar restaurant in an old church at 761 Queen Street West in Toronto. The restaurant served as a physical gathering space in and for the community, where survivors worked and came together around food, as featured in the documentary film *Working like Crazy* (1999). It is now a catering company in the Parkdale neighbourhood of Toronto.

⁶ This event was described in a filmed interview with Diana Capponi. It can be viewed in this short web-based documentary [starting at 14:20]: <https://www.youtube.com/watch?v=YDy6gROcJ-w> (School of Disability Studies, 2009).

⁷ The research study "In the business of changing lives": Activist knowledge-practices and the founding of consumer/survivor businesses in Ontario was approved by York University's Ethics Review Board (Certificate # STU 2021–129).

discovering and mapping social relations. Embracing a social ontology, IE has two main aims: first, to explore and critique ruling relations in their institutional form to enable people to orient their experience to where they want to go, and second, to build knowledge and methods of discovering ruling relations in contemporary society (Smith, 2005).

IE studies often incorporate textual analysis to examine how relations of ruling operate in the every day/night lives of people in specific institutional settings. IE looks to texts (broadly defined) as a material basis of the discourse that shapes ruling relations. Most institutional ethnographies study present day issues, though some historical institutional ethnographic research exists, including those few that have used a combination of oral history and archival research (Kinsman and Gentile, 2010; Luken and Vaughan, 2005, 2006) or have engaged photographs in interviews (McCoy, 1995).

For this study, which required a creative application of historical institutional ethnography (IE) during the COVID-19 pandemic, I conducted interviews using IE interviewing techniques (Campbell and Gregor 2002; DeVault and McCoy, 2006). The analysis of interview data was also informed by IE. Within this article, I am not presenting a textual analysis of archival materials in the IE sense, or attending to how participants use texts in their work. Instead, I reflect on engaging archival materials during the interview process, to argue for this method's applicability more broadly, across qualitative interview methods in sociology, beyond oral history and life story research. By working to preserve the archival materials that were shared with me through this study—as I describe in the final discussion—there exists a possibility for later research and analysis of archival materials. Unlike oral history or life story research, recordings of the interviews were not preserved as testimony. IE interviews honor the stories shared by participants, but the study begins rather than ends at this point. Their stories provide valuable insight into how people understand their experiences, motivations, decision making; however, the purpose of IE is to see how people's work is socially organized—in this case how their activism has been socially organized—so the interview transcript acts as a starting point for analysis, not as an artifact for preservation, nor are they considered the 'truth' of the matter. Reflecting on innovative methods in IE is also important for taking IE methodology in new directions, as new factors such as technological innovations and shifting global contexts such as pandemics, require adapting techniques.

In total, I interviewed 42 participants, some on multiple occasions. These were primarily individual interviews, though three small group conversations took place whereby a number of workers or board members from the same workplace were interviewed together at the same time. All were semi-structured interviews using an interview guide as well as, in many cases, the discussion of some form of archival materials. As is the tradition in IE, interview questions focused on the every day/night work people do (or in this case, have done), where work is defined in the broadest sense as any intentional activities that take time and effort. Interviews were conducted over the phone, over Zoom or in person, depending on participant preferences. I spoke with workers from consumer/survivor businesses as well as leaders and board members from consumer/survivor businesses and CSIs during that time period. I also spoke with people who founded or help to found consumer/survivor businesses, civil servants, policy makers, service providers and academics who were involved as allies supporting these organizations in some way. Participants were given the option of remaining confidential or using their real names; the majority chose to use their real names.

The study involved large quantities of archival materials in a wide variety of formats. As part of the interview consent process, I asked people if they had any materials they would like to share as part of the research. I was taken aback by the generosity of community members who were willing to share all sorts of materials⁸ from their personal collections and consumer/survivor business archives. Viewed collectively, these materials tell a story of activism, acts big and small, by consumer/survivors and the important role consumer/survivor businesses played as sites of community organizing.

This study builds on a longer lineage of community histories of mad activism. Gallagher (2021) explains the significance of local grassroots community history projects such as Oor Mad History in Edinburgh and the Survivor History Group in England for documenting the collective actions of service user/survivor movements through the archiving of primary sources. These projects carve out space for survivors to enter into historical research and re-historicize histories of madness (Voronka and LeFrançois, 2022). Projects such as these work to reclaim subjugated histories, challenge authoritative knowledges with counter-discourses developed in community, and create places where survivors can see themselves reflected as agents of change (Gallagher, 2021). Over the years, fruitful exchanges have taken place between Oor Mad History and Mad Studies projects with similar aims in Toronto, Canada, notably the Toronto Psychiatric Survivor Archives and the development of Mad Studies courses rooted in local activist histories (CAPS Independent Advocacy, 2021). Kathryn Church's extensive work as an independent researcher for consumer/survivor businesses, meticulously documenting their social movement learning, later informed her scholarship in Mad Studies and efforts to secure courses in mad people's history at Toronto Metropolitan University. Gallagher claims Mad Studies "appears to be predicated on the inquirer identifying as mad, or as a survivor, on the basis of their experience of being a psychiatric patient" (2021, p. 254). While it is true that community history projects often prioritize survivor involvement, and for good reason, Mad Studies does not make this demand. Church herself identifies as an ally to the movement. Inquiries grounded in Mad Studies are, however, rooted in community organizing and refuse apolitical understandings of history. This requires meaningful engagement with mad politics and praxis (Costa and Ross, 2023; Voronka and LeFrançois, 2022).

Central to this project has been an effort to centre and preserve local mad activist history. In thinking about the things that make up this history, my research practice has been guided by a relational ethics of care and reciprocity (Caswell et al., 2021; Ellis, 2016). It has determined how to proceed with, tend to, digitize and (only with permission) share materials. Though used here to generate conversation and evoke memories, I recognize the importance of these objects as invested with significance by the people who shared them.

⁸ Items gathered directly from interview participants and consumer/survivor businesses included: films produced by or involving CSIs, radio interviews, c/s business photo albums, loose photographs, newspaper and magazine clippings, books, policy documents, reports, program evaluations, training manuals, political speeches, directories of consumer/survivor initiatives, business plans and proposals, conference proceedings, incorporation documents, fax communications, c/s newsletters, magazines, pamphlets, and other c/s publications, T-shirts, buttons, and more.

This required careful consideration throughout the data gathering and interview process. Before each interview, I gave thought to who I would be meeting with, which organization(s) they had been affiliated with, and if I had any materials that may be relevant to share with them. An ethics of reciprocity, though arguably impossible to achieve in an inequitable world, aims to create mutually beneficial relationships and research practices (Caswell et al., 2021). This also determined how I proceeded with materials. For anyone who shared physical materials as part of the research, upon return I also shared back those materials in digital format. For some organizations with limited capacity to preserve their own history or utilize materials from the past, having digital copies was particularly beneficial.

Uncovering materials and making connections

One example, narrated below, describes how archival materials from personal collections were located through the interview process and engaged through ongoing discussions. In some instances, participants directed me to locate documents corresponding to the stories they were telling. In the first of four interviews I conducted with David Reville, he described how businesses that predated the establishment of the Consumer Survivor Development Initiative (CSDI) had secured financial backing.

“In 1980, The City of Toronto had a little sort of beginning interest in community economic development. And they had a little bit of money to give out. And I think one of the groups they gave money to was On Our Own, which was Don Weitz’s group. And he, they had a little business called the Mad Market. And that would have been the first survivor business in Toronto.” (David Reville, interview participant, 2023).

He suggested I track down evidence of the Mad Market in past issues of *Phoenix Rising*, a Toronto-based consumer/survivor magazine from 1980 to 1990, as well as reference to it in Irit Shimrat’s book *Call me Crazy: Stories from the Mad Movement* (Shimrat, 1997). He later emailed me, expanding on the City’s early investments in consumer/survivor businesses as aligning with a community economic development (CED) approach:

“The city had a small CED program and I believe the Mad Market got \$ from it. And I believe, too, that A-WAY (87) and Fresh Start (89) also got start-up money from the City and I think that was down to Jacques [Tremblay]. ... I don’t know how you’d track it down. If I think of it, I will tell you.” (David Reville, interview participant, 2023).

As he was a past alderman for the City of Toronto prior to the amalgamation of the GTA and a consumer/survivor organizer, I valued David’s insider knowledge. In instances such as these, participants offered suggestions to support the tracking down of relevant historical materials, materials that could fill in or more fully flesh out the stories being told.

In connecting various documents related to the operations of the Mad Market, I was able to trace some of the organization’s advocacy efforts in a weekly newspaper obituary column for Alf Jackson (NOW

magazine, August 14–20, Weitz, 1997). In the obituary, Don Weitz writes about how this first survivor business came to be, when he and his friend Alf founded the Mad Market. Too often I found obituaries to be the places where consumer/survivor advocacy was most clearly expressed, in tributes to the lifelong contributions of consumer/survivors who had passed on. Early efforts to form businesses were relatively scrappy. Consumer/survivors crafted make-shift alternatives, largely due to their exclusion from the mainstream labour market. In recalling the early days of the Mad Market, David described in an interview how this business took shape and was involved in local survivor politics and advocacy efforts.

“Don [Weitz] and his buddy Alf Jackson had a pickup truck. And they, the night before garbage day, they’d go to Rosedale, and they’d pick stuff. And then they, they had a kind of a, they had various arrangements, sometimes they had arrangements with people who ran flea markets, and they’d have a stall. And sometimes they would just set up in a vacant lot. And that went for a number of years. And the Mad Market followed that. And it had one of the people who ran it was a woman named Carol Stubbs that Kathryn [Church] and I knew, and [pause] Carol is in the... [pauses] 1986, I think it was. I hosted a press conference around ECT. And Don and Bonnie Burstow and Carol Stubbs were at that.” (David Reville, interview participant, 2023).

A few days following this interview, David shared a photograph from his personal collection. The interview had prompted him to look back into this story. The photograph, pictured below, was taken inside the media room in the Legislative Assembly of Ontario, where David then served as a Member of Provincial Parliament. He had organized a press conference on January 9, 1986 for members of the Ontario Coalition to Stop Electroshock, which he then followed up with targeted questions in the House to the Minister of Health. Reviewing Hansard for January 10, 1986, I was able to track David’s exact remarks in the House; he was pressing the Minister to implement the recommendations of the Electro-convulsive Therapy Review Committee and the Gerstein Report (Figure 1).



FIGURE 1

Photograph of a press conference inside the Queen’s Park media room, January 9, 1986. Pictured from left to right: Carol Stubbs (then manager of the Mad Market), Dr. Bonnie Burstow, Don Weitz, David Reville, MPP and two unidentified camera operators. From the personal collection of David Reville, shared with permission.

In recalling this event and by pairing it with Hansard, we were able to see a fuller picture of the press conference, its purpose and the significance of the Mad Market's involvement, as representing the interests of local consumer/survivors. Connecting interviews to historical materials from various sources including personal collections, archival and public records felt like peeling wallpaper. Bit by bit, the underlying image started to appear.

This interview informed me of the intentional sequence of events, as an activist intervention, taken up by multiple stakeholders in the community. It was only through the interview that I knew to track and connect disparate documents, linking them to uncover a fuller story, thanks to participant insider knowledge and involvement in historical events. Even as I located additional documents, such as obituaries, they substantiated the story told in the interview, but also provided more depth, detail and meaning.

Uncovering additional materials was not about triangulating interview data, or prioritizing texts as more reliable sources of data. Instead, this process questions the authority of texts by challenging presumptions that texts are factual and memories are fallible. Arguably, qualitative researchers should never singularly rely on material records or personal memories believing them to be 'the truth'. Millar (2006) contends, as do I, that archival records are not and should not be regarded in this way, though it might be tempting to point to them as such. Truth, she argues, exists somewhere between the archival records, the memories of participants, of observers and other available evidence. Engaging archival materials with participants through the interview process served to enhance the data gathered by uncovering a fuller picture of past events.

Results

Arguably, there are many benefits to sharing and discussing archival materials with(in) interviews. Below I describe 3 instances where participants engaged with archival materials in a number of different ways, to the effect of: cultivating access, evoking memories, helping to make sense of materials (by learning about the context, sequencing, and motivations behind actions), and ultimately, producing richer stories about mad activism.

Cultivating access and prompting recall

In some cases, I sent interview participants archival materials in advance of our meeting. Often this was because I was aware the participant was connected to a specific event, action or organization. Having participants take a quick look at an old photograph was at times enough to bring back a flood of memories, giving them more to talk about and in more detail. In a few cases, I did so to address participant's concerns that they might not be able to remember much from that time period, as the call for participants indicated the study focused on the period from 1980 to 2005. Asking people to recall events from 30 + years ago can be challenging for anyone, though this may present additional barriers for older people or people who have experienced a lifetime of psychiatric interventions.

When participants indicated concerns, even minor comments such "I'll warn you my memory is not what it used to be" (interview participant), I made an effort to send a few materials, with their

consent, over email, to aid in resituating them to that time and place. Sometimes this had a surprising effect. After sending one interview participant an old newspaper article, they began the interview by pointing out how much they had hated the article when it came out for misrepresenting a past leader of the consumer/survivor business where they had worked. This response had me see the article in a new light, as the participant reframed the event of the news coverage and was able to critique the 'official' text by reading it in counter-hegemonic ways. In another instance, when I shared newsletters produced by one consumer/survivor business with a past employee of that business, they were able to draw my attention to important parts of documents that I had overlooked.

When I met Graeme Cushing for an interview, I brought along a file folder, as I had already amassed a collection of materials specific to A-WAY Express, a courier company in Toronto, where Graeme has worked for over 30 years. I was aware, from looking at those materials that Graeme had been involved in different forms of advocacy as part of the business. Deferring to the participant's preference, we chose to wait to look at the file folder together at the close of the interview. During the interview, some of the recollections he had of events were limited: "I think there was a protest. It was really hot and we got bottled water for people but this is, this is, I really cannot remember." (Graeme Cushing, interview transcript, 2023). Even limited information such as this could prove helpful though, as it might mean placing the organization he was representing, A-WAY Express, at an event (in this case, Mad Pride Toronto's bed push parade) and later locating news coverage or newsletters related to those events.

In the excerpt below from the interview with Graeme, I make reference to a document which he had not yet seen, from a Senate Committee meeting where he was listed as a speaker, in order to prompt his recollection of the range of advocacy activities he had been involved with.

DL: Okay, so, my next question then is: Do you consider any of the work that you have done to be activism or advocacy. Any part of your work or, you know, something associated with your work? How so?

GC: Well, um I, I think just simply doing your job is a form of advocacy. I think simply day in day out coming as a person with lived experience and doing you're doing a job every single day is testament to that. But also, I mean, there's, there is advocacy. There's, there's, what I'm doing right now is there's public speaking. I've done public speaking before I got up and I've sort of, at AGMs when there's been members of the community there and said, you know, this is why I like to work in A-WAY, this is what it's done for me or that sort of thing. And this is why it's it helps me so much.

DL: Apart from AGMs, were there any other events where you were public speaking? So, for instance, I know I noticed in the archives, once you were at a Senate committee meeting for instance, did you speak at that event?

GC: I think briefly Yeah. Yeah, I think, it was so long ago, so long ago, but I think I did briefly. When I've spoken before. I spoke about working at A-WAY where there was, there was a gathering down at ... have you heard of the Raging Spoon?

DL: Yeah, it was such a great space.

GC: Yeah, at the Raging Spoon. This was when, this was actually in the Mike Harris days when Janet Ecker she was the minister of Canadian social services. Yes. And we were, I was speaking about my job and she was there and you know, so trying to make an impression on hope-hopefully, her that you know, the importance of work, the importance of maybe allowing people to keep a few more dollars of what they make [overlap] because of ODSP.

DL: Exactly, because of the claw back.

GC: Yeah, it is terrible. (Graeme Cushing, interview participant, 2023)

In this example, more specifics became available, such as advocating to ensure their earned income wasn't clawed back under provisions of the Ontario Disability Support Program (ODSP). The intentions behind this intervention, the targets, and specifics of an entirely different event came up following the prompt. I am very interested in how he as a consumer/survivor identifies being a worker as a form of advocacy in and of itself, since it resists sanist and ableist ideas about what mad people are capable of and challenges normative ideas about valuable workers and benefit recipients. While equally valid, throughout the interview process I had become mindful of a need to push participants beyond the kinds of canned narratives⁹ or stock stories that they rely on from the past, such as the ones they use on behalf of the business. Mentioning the archival material worked to move the conversation beyond a more rehearsed narrative where he has represented himself as a member of the organization and as a person with lived experience.

Making sense of materials, evoking memories and meaning

In this next example, I describe how archival materials came up for discussion in my interview with Charmaine Frado. Charmaine started up both the Ideas Work Studio and Inspirations Women's Collective (now Inspirations Studio), which began as a craft collective for un-housed women with mental health histories over 30 years ago. Prior to our interview, I sent Charmaine a few photographs over email. These were group photographs featuring Charmaine and other members of Inspirations which I had located in Working for Change's archive. Toward the end of our Zoom call, she mentioned the effect of seeing those photographs.

"We knew years ago that people did not live, live their full life potential with mental health histories, right? Diana [Capponi], that was one of the first things she warned me about. She said, 'Don't expect to know people for very long.' And it was a horrible reality."

And so, it's funny when you, when I first got your email, and [another participant] told me all about this, I, I started thinking about people and how many of them are gone. And in fact, your photos, the photos you sent me. I was like, 'Oh, they're gone [pointing gestures]. They're gone.' And I thought, 'Oh, my God, this is heartbreaking.' Right?" (Charmaine Frado, interview participant, 2023)

Though well aware of the shorter life expectancies of consumer/survivors, I had not considered the potential risk in this instance, as Charmaine is only in her mid-fifties. She went on to affirm that this was the reality, and seeing the photographs helped her to remember people. *"You remember your history with the people and you remember them with respect for what they did while they were here."* (Charmaine Frado, interview participant, 2023).

During the interview, I asked Charmaine about her work to develop a safe house called Edmond Place.

Charmaine spoke about Edmond Wai-Kong Yu, a 35-year-old consumer/survivor whom she had known before his death at the hands of Toronto Police. Following Edmond's death there was an inquest and his death was ruled a homicide. The coroner's jury recommendations included the need to develop housing for people in Edmond's position, specifically people who were homeless, had severe persistent mental health issues and could not access services or were accessing them in ways that were not helpful to them¹⁰. She described how consumer/survivors in the community gathered together at Parkdale Activity Recreation Centre (PARC) where Edmond had been a regular fixture. People began to meet regularly to plan a safe house project based on the Soteria House model in California. PARC was able to secure some funding to hire someone to coordinate the project, which Charmaine then applied to and was hired to undertake. She referred to this as a "dream project," though no one knew at the time if it would ever become a reality. She went on to describe the long haul of working on the project for nearly 10 years, overcoming many hurdles securing financing and a building site until they eventually opened Edmond Place in 2010. The redesigned heritage building now offers 29 units of permanent, affordable self-contained supportive housing on a site which had previously been an overcrowded boarding house partially destroyed by a deadly fire.

During the interview she brought out a photo of Edmond that she kept on her desk to this day, despite living in a different city decades later. *"No matter where I go, no matter what I do—Edmond goes with me."* She tearfully stated: *"I firmly believe that there has to be a place in the world for the Edmonds."* (Charmaine Frado, interview participant, 2023).

Interviews helped to make sense of the material history of consumer/survivor activism, the significance of these materials and people's connections to them. In the case of Edmond Yu, the public

⁹ By canned narratives or stock stories, I am referring to narratives of the self that people have readily at hand as they have been previously reproduced. These are the kinds of stories that get shored up for a particular audience and may be used strategically, but are limiting.

¹⁰ "8. The Ministries of Health and Community and Social Services should continue funding for the purchase and construction of new housing for consumer/survivors in Toronto. Such housing should include short-term 'safe-house' facilities such as the Gerstein Centre. Rationale: Housing is not always affordable and is difficult to obtain and retain because consumer survivors are not always seen as desirable tenants. Housing is a mental health issue and the absence of decent housing is a major determinant of health." Verdict of Coroner's Jury. 1999, April 16. Coroner of Ontario.

and community outrage following his death led to many forms of activism and a recognition for the need for anti-racism work within consumer/survivor spaces and better cross-movement organizing. Other interview participants also shared documents related to Edmond Yu's death with me, including a report on Edmond Place, a copy of the Verdict of the Coroner's Jury, and an anti-racism training manual for workers at one of the consumer/survivor businesses. The training manual includes the case of Edmond Yu's death, to explain the intersecting nature of racism and sanism. Connecting these various materials through interviews helped to provide context, offering a bigger picture of the sequencing of events and their motivating force.

In this study, I found time and time again how grief, outrage and memory of community members who had died prematurely were drivers for advocacy and collective efforts towards system change. In Charmaine's case, she dedicated 10 years towards building a safe house in Edmond's name and continued to carry his memory—and a photographic reminder of it—into her future work. In this way, participants reminded me of the significance of archival materials from personal collections. Discussing materials in interviews served to deepen participant stories and emphasized the meaning and impact of loss in consumer/survivor communities.

Bringing survivors' perspectives and knowledge back into the conversation

In a final example, I used recorded footage of Diana Capponi, past ED of the Ontario Council of Alternative Businesses (OCAB) from 2009, speaking as part of a filmed interview for a short web-based documentary. Diana died in 2014. In the footage, Diana narrated how Out of This World Café was created as the first consumer/survivor business (to her knowledge) to be established inside a mental hospital—Canada's largest mental hospital, the Center for Addiction and Mental Health (CAMH). She describes how it took many years of convincing to get the hospital to divest from their canteen.

The knowledge-practices (Casas-Cortés et al., 2008) of consumer/survivor activists are rarely captured and credited in formal academic or even grey literature. Due to shorter life expectancies (Chang et al., 2011; Hjorthøj et al., 2017), their knowledges are less likely to be documented or preserved before their passing. As part of this study, I interviewed the past CEO of CAMH during that time period, Paul Garfinkel. In my interview with Dr. Garfinkel, I asked him what he recalled about the handover of the canteen business to OCAB (now Working for Change) which subsequently became Out of This World Café. Looking through Working for Change's archival records, I had seen photos of him at the ribbon cutting ceremony, so I was aware he had been involved, even peripherally, as his Community Relations team managed the handover. His recollection was very limited:

"I don't remember it at all. I remember there was a canteen? But I didn't, I don't even associate it with Out of This World Café. I see it as a totally different phenomenon, sorry." (Paul Garfinkel, interview participant, 2023)

I also asked him if there were any lasting effects or impacts from the working relationships between CAMH and OCAB. *"Yeah, I would say they gave us an awareness and confidence to do more."* (Paul Garfinkel, interview transcript, 2023). He went on to describe a

number of community involved projects that had been developed at CAMH under his leadership in the years that followed the opening of the café, emphasizing, *"I do not think we would have done that if we had not had the experience with Out of This World."* (Paul Garfinkel, interview transcript, 2023). He continued to refer to a progression from that positive experience with one consumer/survivor-led business towards less institutional hesitation overall with consumer participation, noting how *"it brings staff along in an important way."* (Paul Garfinkel, interview participant, 2023).

Towards the end in the interview, with his permission, I played the 2-min video clip where Diana Capponi tells the story of Out of This World Café's establishment, from her vantage point:

"I had advocated for a long time that the canteen here should be a business that could help train people and provide employment for folks. The argument back was, that's not really, we're not integrating people back into the community, if they're working here, it wouldn't be healthy for them to work here. And I would always challenge that and say, we need to divide up the economy here. If it's healthy for you, it would be healthy for me. Over time, my understanding is a lot of the volunteers died off. Here at CAMH there was a, an attempt to develop a community development corporation within the institution. And that community development corporation's first initiative was the canteen, and for five years, they paid people cash weekly, under the guise of trainees. ... And so, they got into a little bit of trouble with Revenue Canada. And at that point, OCAB was approached and asked if we would assume responsibility or ownership." (Diana Capponi, filmed interview July 2009, onsite at CAMH)

Viewing the clip clearly brought back sensory memories for Dr. Garfinkel who acknowledged it was the first time he had 'seen' Diana since her passing. He went on to reiterate in a bit more detail:

"The only thing I knew was about Revenue Canada and the canteen. I was in a role where, you know, where they brought you problems. And that's maybe all you heard about. So I knew they had trouble and then I knew we had this new business. I hadn't linked them actually in my mind. [pause] What she says is completely right. People at one point had hesitation and as I said, by the time of this, hesitation at least for me was gone." (Paul Garfinkel, interview participant, 2023).

My decision with this interview to use filmed archival footage was deliberate and specific: to bring Diana's voice back into the conversation. It's not that viewing the video changed Dr. Garfinkel's story, though he was able to expand on what he could remember, elaborating on earlier points. In this case the use of archival material as prompt was not to address access barriers, but it still proved beneficial. Dr. Garfinkel's response provides insight into higher level decision making and he corroborated the story of a consumer/survivor leader, whose voice would otherwise no longer be part of the conversation.

Discussion

As previously stated, engaging archival materials in interviews in this way is not about triangulating my data, or seeing any one story or

document as ‘the fact’ of the matter. Rather, doing so served to peel away the wallpaper, so to speak, to uncover a fuller picture, to gain a deeper understanding of how consumer/survivor advocacy was socially organized and to center and honour consumer/survivor histories.

Numerous challenges came up throughout this process and are worth noting. Gathering and engaging archival materials from personal collections led to more complex data collection and simply a larger volume of data than originally anticipated. It was time consuming and required gathering additional resources and partners to support the preservation and digitization of archival materials when consent was given. There were also risks that were not fully anticipated, such as in Charmaine’s case when participants, upon seeing old photographs, are struck by how few people remain alive.

Despite these challenges, six benefits to discussing archival materials within qualitative interviews were identified. First, bringing archival materials into view facilitated the gathering of additional materials from participants’ and business’ collections. Many of these materials had been tucked away long ago by people involved in consumer/survivor business and CSI activities. Amidst the closures of many businesses and the precarity of many consumer/survivors’ lives, these multimedia materials may never have otherwise been shared publicly or preserved digitally. When consent is given, the multimedia formats of archival records offer rich possibilities for knowledge translation and mobilization that go well beyond the limits of academic publishing, fostering new forms of public sociology. A second benefit is accessibility, as archival materials can serve as memory aids during the interview. Further, all sorts of people may benefit from resituating themselves in time and place through archival materials prior to speaking on events from the past. Third, some participants were able to speak more concretely or in more detail about their recollections when material histories were shared, aiding to bring memories to the forefront. Fourth, the pairing of archival materials and interviews served to breathe life into the story. Ethnographic narratives become more textured and vibrant when interviews go further in depth and materials can be used to illustrate examples. Fifth, participants can aid the researcher in making sense of materials, by narrating the sequence of events, describing the connections between seemingly disparate documents or by pointing out elements of interest. And lastly, a sixth benefit related to historical research where many of the people involved are no longer alive, is that materials can be used to bring their contributions and perspectives to light.

The central role of an archival institution, according to Millar, “ought to be to seek out the records of its society and make those records *accessible* so that the society may *use* them not just to document events but also to interpret, shape, and articulate memories” (2006:122) [emphasis added]. This paper argues there is a sociological significance to collectively remembering, preserving and sharing mad activist knowledges and histories (Choudhury, 2015), in light of the precarity of mad people’s lives and the political economic systems that erode them. My work aims to take up that imperative in some small way. Arguably, mad and disabled people’s activism alters our understanding of ‘what counts’ as activism, to see every day activism as world making (Dokumaci, 2023). Mad and disabled people must constantly improvise habitable worlds for themselves and institutional ethnographic methodology reminds us there is significance in

documenting the complexity of these labours. Sociological studies that center madness and disability are needed in that they serve to expose and disrupt a normative order.

This article contributes to historical research on mad activism by thinking through the possibilities and effects of engaging archival materials in interviews. Narrating three examples above brought into view the kinds of activities local mad activists undertook during the ‘consumer phase’ of the consumer/survivor/ex-patient movement in Ontario. Accounting for consumer/survivor businesses past and present, as this study has done, is important work, in part because this history is at risk of being lost. Table 1 compiled the list of consumer/survivor businesses in Ontario from archival materials and the accounts of interview participants. As indicated, only eight of twenty-five businesses remain. Foregrounding this unique organizational form, I argue these sites played a central role in local consumer/survivor activism throughout the 1990s.

My interview participants were incredibly generous in terms of entrusting me with the material history of these businesses and their community organizing efforts, which has not yet been properly documented in any formal archives. I feel a deep sense of responsibility to honour the community involvement, work and activist contributions of consumer/survivors and those who shared these material histories with me. Through mentorship by mad activists and academics, I have been taught that mad community knowledges and histories belong to those communities (Reville, 2021). So early in the research process, I struck up a partnership with Madness Canada¹¹, to secure a permanent home for a digital archive of consumer/survivor business activism¹². A second consent form was provided to research participants who wanted to see any materials preserved and shared in a publicly accessible format. Being guided by a relational ethics of care means I recognize how precious these materials are and feel a responsibility to see this through, as I co-curate this digital archive with consenting participants. I am grateful that the development of this digital archive will eventually help to bring this little known local mad activist history to light.

Data availability statement

The datasets presented in this article are not readily available because the participants of this study did not give written consent for interview data to be shared, so due to the sensitive nature of the research, supporting data is not available. Requests to access the datasets should be directed to Danielle Landry, dlandry@torontomu.ca.

Ethics statement

This study involving humans was approved by York University Research Ethics Board. The study was conducted in accordance with the local legislation and institutional requirements. The participants

¹¹ Madness Canada: <https://madnesscanada.com/>.

¹² The digital archive is currently in development with a provisional launch date of 2026.

provided their written informed consent to participate in this study. Written informed consent was obtained from individuals for the publication of any potentially identifiable images or data included in this article.

Author contributions

DL: Conceptualization, Funding acquisition, Project administration, Investigation, Data curation, Formal analysis, Writing – original draft, Writing – review & editing.

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Conflict of interest

The author declares that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Indigenous narratives of mental illness: narratives from Naga tribes

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indigenous knowledge, Naga tribal healing practices, mental health and culture, community mental health, traditional healing for mental illness, traditional healing knowledge

1 Introduction

Native viewpoints on mental illness, particularly those based in relational, spiritual, and communal worldview have been historically denied space in mainstream psychiatric discourse. This article examines how the northeast Indian Naga people think about and treat mental distress, privileging healing as a cosmological, communal process over an individual, biomedical one. Drawing on narrative accounts and ethnographic knowledge, we seek to critically interact with indigenous epistemologies of mental health and demand a more plural, culturally sensitive framework in mental health discourse. As a team comprising a Naga scholar, a psychologist, and a researcher in indigenous knowledge systems, our perspectives are shaped by both lived experience and academic engagement. This multi-disciplinary lens informs our commitment to critically engaging with indigenous epistemologies and mental health narratives.

Psychopathology may usually be the biological picture; but for mental illness to be truly understood, it has to be culturally sanctioned and accepted. Among the Naga tribes in northeast India, mental illness is far from a problem pertaining to neurotransmitters or diagnostic nosology; it is a spirit-fueled communal experience. Our contention is that, far from being an inferior conception of mental illness, the traditional Naga healing practices constitute a culturally coherent model of emotional distress and recovery. The real worth of these healing practices rests not just on historical grounds but in the prospect that they may contribute meaningfully to present discussions on mental health (Longkumer and Rao, 2019).

Mental health among the Naga communities is deeply embedded in cosmological beliefs, clan-based responsibilities, and reciprocal social relationships. Illness is not viewed in isolation but as a disruption in the moral, spiritual, and social order. Shamanic interventions, ancestral rituals, and communal participation are central to addressing mental distress reflecting an understanding that healing is a collective process. Such practices, often dismissed in mainstream psychiatric discourse, offer alternative paradigms of care that prioritize meaning-making, social cohesion, and spiritual balance over pharmacological intervention. Ignoring these systems risks not only epistemic injustice but also the loss of context-specific insights into human suffering and resilience (Bhakuni and Abimbola, 2021).

By putting indigenous voices and stories first, this article aims to initiate discussion on the predominance of Western biomedical paradigms and the need for pluralistic mental health models. Based on narrative accounts and ethnographic impressions from Naga

elders, practitioners of traditional healing, and community members, we discuss how local cosmologies interpret and treat mental distress. Instead of presenting itself as filling disciplinary lacunae, this article calls for critical examination of the necessity to decolonize psychological knowledge and incorporate culturally grounded concepts of healing into mental health discourse.

2 Traditional beliefs: beyond superstition

Indigenous perspectives, esp., from the vantage of modern psychiatry, are easily dismissed as superstitions. However, such an approach is far too reductive. Among the Nagas, shadowing spirit possession, soul loss, or ancestral wrath are not irrational fears; rather, they are explanations based on hundreds of years of lived experiences (Ao, 2009). Mental disturbance is viewed as something that disrupts social and spiritual harmony; it is not some flaw that is strictly internal to a person (Kumar, 2005; Singh and Indian Council of Social Science Research, 2008). The difference from Western pathology lies in the fact that the former really do emphasize interconnectedness instead of individualism.

Nagas believe in the spirit world, soul loss, or wrath of ancestors on grounds of a coherent cultural system in which mental disturbance results from a disruption in spiritual harmony (Longkumer and Rao, 2019). A household survey of 510 rural and 300 urban households in Nagaland in 2017 found that 58.9% of rural respondents and 24% of urban respondents regarded traditional healers as the major consulting group, especially in view of mood disorders thought to be caused by spirit interference (Longkumer and Rao, 2019). These systems are not merely superstitions but culturally based explanations with some diagnostic power and social relevance.

3 Healing as a cultural ritual, not a cure

Traditional Naga methods of healing gravitate more toward maintaining equilibrium than toward curing. Shamans and healers thus assume crucial roles, not merely as therapists but as moral and spiritual guides. The ritual processes they perform whether soul retrieval, spirit appeasement, or herbal treatments all serve to reintegrate the affected individual back into the community and cosmos (Shimray, 2002). These, in essence, are symbolic acts of healing that contemporary psychotherapy imitates through narrative reconstruction and emotional catharsis (Aldwin, 2016).

In Naga culture, mental health is community-oriented, wherein family, clan, and village heal together. Longkumer and Rao (2019) study substantiates that mental distress is addressed by the collective, with rigorous follow-ups undertaken and the entire village involved in supporting the patient. This resembles peer-supported learning approaches today: for instance, SCERT Nagaland incorporates peer counseling and movement therapy into its diploma syllabus, thus acknowledging indigenous practices in formal education settings (Longkumer and Rao, 2019).

4 The community's role in mental health

With its collective accountability, one of the distinctive aspects of the Naga way is that the family, clan, or village is engaged in the healing process. The traditional concept of mental illness is that it is a disturbance that affects the entire community, not just the “sick” individual. This is in stark contrast to the isolation patients may often experience in clinical systems (Adhikari, 2023). When loneliness, disconnection, and alienation are global health crises in themselves, the Naga paradigm points to the worldwide therapeutic promise held by communal care (Kienzler, 2008).

Naga traditional healing largely relies on herbal and spiritual remedies. According to Longkumer and Rao (2019), herbal remedies and manual therapies are practiced alongside psycho-spiritual techniques. For example, a mixture of honey, local roots, and substances derived from insects is used along with chanting and rituals, clearly indicating how spiritual constructs are strongly identified with ethnobotanical healing (Jamir and Watienla, 2019).

5 Modern psychiatry and the risk of cultural erasure

The slow decline of conventional healing practices can be traced to Western psychiatry and religious conversion, both of which have been known to stigmatize these practices as *passe* or *pagan* at times. In contemporary times, many healing rituals are simply branded as “demonic” or “pagan” (Longkumer and Rao, 2019). This is indeed a troubling line of thought. Modern psychiatry may have its merits, but it often shows little regard for native epistemologies or ways of knowing (Gone, 2013). The question, however, is not about choosing one, but rather creating an avenue for dialogue between science, tradition, shamans, and psychologists.

In Nagaland, the introduction of Western medicine and Christian religion has led to the marginalization of traditional healing methods. Ritu (2025) observes numerous rituals are now abandoned or labeled as ‘pagan,’ with younger generations even less familiar with traditional knowledge systems. There is a warning from scholars that this failure to respectfully integrate these practices into formal mental health systems might lead to the erasure of centuries of local epistemologies (Longkumer and Rao, 2019; Ritu, 2025).

6 Conclusion: bridging the healing worlds

From our perspective, the traditional psychopathological model of the Naga tribes stands not only for an alternative way of understanding mental illness but also challenges Western dominance over psychiatric narratives. It makes us realize that mental health can no longer be considered as merely biochemical; it becomes existential and communal. It is time for us as researchers, mental health workers, or simply as fellow humans navigating distress to learn from models that embrace complexity, community, and culture. The future of mental

health hinges upon our willingness to listen, whether it be to the doctor or to the traditional healer (Gone, 2013; Kumar, 2005).

Indeed, the traditional healer is still considered viable. Many rural and some urban residents in Nagaland still view traditional healers as effective sources of mental health care, particularly for spirit-related afflictions (Longkumer and Rao, 2019). Integration is being proposed, with only 40 percent of healers supporting such models if there is mutual respect and safeguard of intellectual property (Longkumer and Rao, 2019). WHO (WHO Strategy 2025–20234) has implemented policies to take forward the development of evidence based practice of traditional medicines, we really hope there will be more scientific integration of indigenous traditional healing practices to mental health care.

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Selfhood and inclusive publics: a critical disability lens and creative practice to ground collaborative homelessness research

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This paper explores homelessness, research and advocacy with a critical disability lens. It reflects on several years of public space research, and advocacy in national and local networks of homelessness service providers, homeless people, and activists in Johannesburg, South Africa. The paper builds on a triad of self-(an) other-collective to unpack how sacrificing aspects of the self in conditions of extreme inequality and polarization is key for building broader collectives and inclusion. Reflecting on disability as a cause and consequence of homelessness, I offer insights from within and beyond research methods on everyday practices of community wellbeing. Firstly, at the level of community amongst public dwellers and interactions with individual service providers, and secondly through networks of practice-based organisations. The social model of disability clarifies systems of exclusion, de-pathologizing people living with homelessness, critical for expanding publics and inclusion. The paper explores moving towards collaborative and co-created research, guided by community and creative practice, drawing from the intersection of theory and practice around homelessness and disability. It also examines how the sustainability of collaboration also rests on internal shifts, which this paper explores through autoethnographic analysis of the author's merging art and research practices. While practising public art has been valuable in building relationships in public space research, my art practice also aids in healing my own psycho-spiritual self and bringing me more into community. The paper also follows Paula Toledo in centering curiosity as a basis for compassion and connection, key for substantive collaboration across difference, which also requires openness and honesty about complicity in conditions of inequality. It concludes by drawing out methodological implications from the intersection of these ideas, arguing for greater attention in research to time, play, creativity, openness about personal connection, and the importance of collaboration.

KEYWORDS

homelessness, research, advocacy, critical disability, public space research, networks of homelessness service providers, homeless people, creative practice

1 Introduction

One of the most striking absences in my research on Johannesburg's inner-city public space was public toilets. Over the course of this research spanning my masters, PhD and first postdoctoral position between 2015 and 2022, I became increasingly aware of how the lack of public toilets was entangled with the way acceptable behaviour was understood and policed. Particularly, how

homeless¹ people were criminalised through being forced by circumstance to conduct private activities, such as their ablutions, in public spaces. This denial of access to public toilets in the face of circumstances (homelessness) that demand its necessity resonates with how many of the barriers faced by disabled people are based in their denial of access according to social structures and prejudice that shape forces of marginalization. Importantly, ways in which homeless people and disabled people are marginalized tend to obscure the skills, creativity, resilience and value of people, which allows prejudice to further take hold and exacerbate the same marginalization.

These forms of marginalization are linked to contexts of individualism, where many systems, especially in the neoliberal order, reward and acknowledge individual success at the same time as exacerbating injustices such as the impact of the housing crisis on homeless people, and the uneven impacts of climate change on marginalized people around the world (Bezgrebelna et al., 2023). Furthermore, homelessness as well as madness (or other forms of disability) are often presented under neoliberalism as the result of individual failure rather than structural conditions (Martin, 2022). This in turn is related to humanity's fears and anxieties about scarcity, health, access, safety and survival, along with ideological polarization, which exacerbates an 'us-and-them' syndrome (e.g., Ling, 2023; Runswick-Cole, 2014). Because (social) research is conducted by people who bring aspects of themselves to their work, this paper explores personal circumstances and actions that can support shifts towards more collaborative, inter-disciplinary research based on more centring of lived experience (Martin, 2022). Critically, this centring must not preclude collaboration across difference.

This paper explores how internal shifts are important in moving towards collaboration, and how this ties research and life more closely together. This drives the key argument that mutually constitutive practices of wellbeing both rest on internal shifts towards others, as well as necessitating interdependence and collaboration across difference. I explore how my art practice, concurrent to my research work over the past decade, prompted and shaped internal shifts in my own life. At the same time, I touch on the resistance, solidarity, and communities of care I observed in the context of homelessness that also speak to the constitution of inclusive publics. In reflecting on a long period of research and practice, the paper is a theorisation of the connection between methods, ethics, and values in research over time. It aims to bring critical disability studies, creative practice, homelessness research and advocacy, into conversation, using autoethnography to reveal methodological insights for research aimed at community wellbeing.

An important dimension of my public space research and my art practice has been considering the relationships between individuals and collectives; the thresholds between selves and others. This paper draws on the ideas informing my entry into public space as a researcher, which began a long-term process where my praxis and theoretical endeavour

shaped each other in a process of iterative feedback. Importantly, this iterative process brought me closer to the people and communities I was working with, constituting an entry into public space as a member of the public. This was shaped, and in turn played a role in shaping, my personal art practice. As such, the paper uses critical autoethnography (Maréchal, 2010) to trace my academic journey and it is merging over time with my artistic practice. It starts by exploring my entry-point as a historian into researching public space, and how this intersected with my collecting and painting work, ultimately shaping how I understand the research process and city around me (Middelmann, 2019, 2024). From there I examine my deepening research into public space and the threshold of publicness and privateness, between the self and other in space. This process also allowed me to recenter my appreciation for mystery and curiosity in the complex entanglements of urban space, finding further resonance between artistic, academic, and personal development. It is important to note that 'clear and safe boundaries' for protecting oneself and one's energy are key for moving towards and with others (Cassina, 2022: 20).

This trajectory has taken me towards focus on the links between individual and collective wellbeing, especially in contexts of inequality and difference. This has fundamentally shaped my research practice towards greater collaboration, deepening my mutual use of public space with others while finding opportunities to work in community on issues facing people using these same public spaces. This connection of research with impact on real life issues is a shift occurring on wider scales (Brenninkmeijer, 2022), and here I explore the nature of this connection in my own work. This involves discussing the work that happens around the edges of our research, without being a central or official part of a particular research project. In other words, why do we choose to do the research that we do, and how does this relate to how we live our lives? This paper interrogates implications for research methods that stem from exploring one's own connection to their research and its participants through a triad of self, other, and collective. Also, it explores how these are shaped by structural and systemic realities at different scales, including university employment and neoliberal capitalism. As such, the paper looks at debility (in the sense of how these contexts and circumstances are debilitating) and disability (in the sense of differences which have not been accommodated for, creating disability) (Puar, 2017), showing how these interrelate with homelessness, society and research.

2 Background: individualism and public life in research and art

Starting with an interest in public memory and undergraduate training in history, I began researching public space in Johannesburg at a human rights and heritage precinct named Constitution Hill in 2015. This expanded from 2017 to research a wider selection and variety of public places. These included a large park, a large open square and bus terminus, Constitution Hill, and a section of street and pavement that connected the three (Middelmann, 2020). The overarching research question was investigating the interplay between history, design, management and use of public space, with a spatial justice lens. The case study selection was aimed at having a wide variety of public space typologies (park, square, transport hub, heritage site, street, etc.), as well as choosing some of the largest and more significant public spaces in the inner city. Selection of research participants was done through iterative ethnographic research in the different spaces over the period 2015–2022, visiting each space regularly throughout,

1 There remains tension between perspectives on terminology for homeless people, which I have referred elsewhere in this paper to as public dwellers (and in Middelmann, 2022b), reflecting some reality of their living situation. Terms like unhoused help to start specifying some complexity of the multiple types, causes and consequences of homelessness. This paper uses different terms according to context, also aiming to connect to multiple discourses that may each employ different language.



FIGURE 1

On the left is a collection from a day's research in 2018 of playing card (the significance of playing cards, both discarded and collected, is reflected on in Middelmann (2024), which also discusses the links between collecting, research, and artistic production.), spring and ubiquitous Johannesburg-style pamphlet. On the right is a collage juxtaposing collected objects from research-fieldwork with author's hand-drawn map of the research area.

discussed further below. The author gradually moved from relatively organic and chance interactions to encounters guided more explicitly by emergent research questions. Ethnographic research was buttressed and triangulated by interviewing a wide variety of practitioners, public space users and managers, staff of relevant organisations, and experts, as well as archival research on the history, design and construction of the spaces. A key theoretical endeavour that started with this research, and is continued in this paper, is about exploring the shifting meanings of publicness and privateness, and also focusing on the threshold of interaction between public and private. I explore this threshold in the paper by looking at how individuals (private) interact with others and form collectives (public).

During this period (2017–2020), I was exploring how my largely studio-based, visual art practices of painting and drawing were merging with my research practice, in turn becoming more public-facing and influenced by my relationship with public spaces and publics. Part of this was about bringing different parts of myself together, and also about bringing my life and work closer together, important for ethnographic public space research and my autoethnographic reflection (Morreira, 2012). I had been practicing urban collecting since childhood, fascinated by the objects discarded and lost in public space, but only during my PhD did I realise how this kind of observational, collecting and juxtaposition practice was part of my research on public space (Figure 1; see Middelmann, 2024). Important in the shift towards sharing my art, collaborating with others, and working in more public-facing ways, was starting to practice land art in public spaces with increasing regularity. Land art involves drawing and sculpting with found, natural, local materials; the practice of this art was formative for me in how I interacted with my surroundings, both human and non-human. This evokes Siebers' concept of "complex embodiment," described by Kim et al. (2021: 10) as 'the reciprocal dynamic between environments and the human subjects who inhabit

and create them.' Crucial for my work was simply spending more time, and slower time (Piepzna-Samarasinha, 2019), being present in my surroundings, which facilitated deeper reflection on the nature of my relationships with people.²

These shifts were important for my ethnographic immersion in the public spaces I was researching (Scholl et al., 2014), and also for my autoethnographic work which involved considering how my art practice had *already* been facing others by drawing on paper in semi-private spaces. By drawing and sculpting in public space through land art, it could turn further outward, which has expanded the range and nature of my social connections, partly by expanding my connection with non-human surroundings. Indeed, this type of practice has been one that also has brought me into a range of interactions with other humans in the spaces I make land art (e.g., Figure 2 below). This has been important to my art, research, and life, which I cannot disentangle. Indeed, in highlighting the importance of autoethnography in this work, I follow May (2023) who argues that the type of practice-based research I reflect on here can usefully incorporate autoethnography, especially in demonstrating entanglement between different aspects of practice with the body and mind doing the work. This kind of experimental, playful, creative presence in public space straddles the boundary between the idea of a researcher who leaves no trace and one who acknowledges that their presence and actions have significant impacts.

Both my art and research began as individualised practices, fairly common for both fields of work. In academia, this is necessitated by evaluation and impact measurements that value individual success, linked to requirements of obtaining degrees to

² And beings, and space, and energy, and rocks and plants, though there is not space to deal with these in this article.



FIGURE 2

Author building stone balance sculptures in Emmarentia Gardens, Johannesburg 2018. Intentionally making land-art in spaces frequented by other people was part of my turn towards others as an artist *and* researcher, partly through sharing my authentic self through creative practice.

build one's individual profile to secure academic jobs; in needing to continue churning out journal publications, which supports competition more than collaboration (Riles, 2022; Kemp, 2013). This focus on individual brilliance in academia also comes with exclusion of women and minorities and is tied up with ableism: 'the fascination with brilliance in philosophy and other areas could conceivably create an atmosphere in which displays of intellectual prowess are rewarded and imperfections are to be avoided at all costs' (Cimpian and Leslie, 2017: 62). Where ways of being and thinking do not correspond with social norms shaped by academic departments dominated by white male leadership, narrow interests undermine inclusion (*ibid.*). However, collaboration by researchers with communities is growing, with calls for more focus on relationship building and less on metrics and publications (Lewis and Sadler, 2021). For artists, much is also dependent on one's personal profile, with connotations of individual brilliance, unique talent, or even genius. Self-expression is often regarded as a core of artistic practice, despite there being many historical and current practises of art that are more communal, collectivist, and focused on social justice. These individualistic framings link with the 'broad cultural logics of autonomy, self-sufficiency and independence' that are denoted by ableism (Whitney et al., 2019: 1478), which also shape prejudiced attitudes towards homeless people, and contribute to conditions that undermine communities of wellbeing. This demonstrates the impacts of disability and disablism as well as highlighting debility, discussed further below.

For many years I was compelled by these notions of individual success, partly because these are still powerful in society, and partly because I am at an early stage of my career following the individualised task of attaining a PhD. Also, because of how societal circumstances tend toward placing responsibility on individuals for inculcating systemic change, regardless of circumstances of power (Argüelles et al., 2017). As such, individualism extends beyond sectors like art and research, connecting to discourses around wellbeing and wellness, the distinction between them demonstrating some tension in relationships between individuals and collectives (Mayson, 2021). Where wellbeing demonstrates a connection between individual and communal health, wellness is often targeted and marketed at individuals as part of capitalist entrepreneurialism. As Dorkatch (2024) has stated, 'wellness culture today is radically individualised and it is kind of narcissistic and inward focused, and it leaves behind the broader systemic factors'. This paper explores the potential for individual shifts towards focusing on systemic factors as part of research and action towards collective solidarity and wellbeing. While critiquing responsibilization, the paper is wary of how such critiques can be used towards absolving ourselves of a reasonable level of responsibility towards collective issues (Mustalahti et al., 2020), which is also problematic.

I am in an ongoing process of trying to extricate myself from embeddedness in individualistic framings of success and wellbeing, notwithstanding various pressures and limits that affect the process. This involves reflecting on how my individualism, and moves away from it, have been shaped by and shaped my research methods and

practice. It has been daunting to consider sacrificing some of my attempts to prove myself as an individual, concerned about what would happen if my contributions were ‘reduced’ to being an ‘*et al*’ or merely a contributor, potentially undermining my fantasy of being the author, creator, inventor, standing alone in my newly recognised brilliance. Yet as these shifts have found space to take root, I have been more deeply connected to others and at the same time more deeply connected to myself. This involves spending honest, reflexive time with oneself, and spending honest, open time with others, and allowing those processes to inform each other, which is where community is formed. Atkinson et al. (2024 unpaginated) further this by using the idea of *crip time* to explore ways of slowing down and resisting neoliberalism:

‘rest, recuperation and recovery time considers how we are thinking about ethical pacing and ways of working together. ... to push the boundaries of what’s possible (or not) in the neoliberal academy and to play with the temporalities of normative research processes which are typically fast-paced and output-oriented.’

Accordingly, time is a key methodological issue that this paper draws out, arguing to protect the time it takes to develop genuine connections that can transcend the strictures of research agreements, funding deadlines, authorship negotiations. In places of deep division, simple presence can start connections across difference. Spending slow time in public spaces, at the pace of those living in or using those spaces, connects *crip time* with the common community-based research refrain of ‘meeting people where they are’. As such, presence in public space was the beginning of an iterative approach to research methods, whether deliberate in terms of aiming to connect with the rhythms of regular users of each space, or more playful through creative practice and simply being myself in public space.

Practicing art in public space, i.e., playfully exploring my manner of presence (Stanford, 2016), was foundational to me finding ways to spend time in public space as a member of that public. The connection of play and art has been inspiring in finding ways to connect with others, and also with my inner-child-like sense of wonder, curiosity, and learning, which I think are important qualities for adults, especially seeking to practice inclusion (see Figure 3). Fearn (2022: 129) explores how this involves moving outwards towards others as well as inwards towards better knowledge of self:

‘play narratives blur the boundaries between human and other-than-human, providing evidence of the flow of communication and identification between children and other species. This supports a felt sense of connection and, exploration of sameness and difference engenders a sense of belonging and a gateway to enter the spiritual life’

Fearn (2022) (*ibid.*: 125) teases out the interplay between selves and others, public and private, that is always in flux; a ‘flow from inner to outer worlds and back again’ that this paper explores through the triad of self, other and collective discussed below. Without art, and as such play, I was often, like many other South Africans (and people in various parts of an increasingly polarized world), hamstrung by the tension of division and inequality in public space that often leads to a retreat into privacy, especially by white, relatively wealthy people like myself (Landman, 2019). As such, the internal shifts discussed in this

paper were about finding my own belonging in a way that opened me into interaction with others. The way this relied on a merging of my art and research practices connects with how ‘political participation is increasingly intertwined with identity, self-expression and everyday life’ (Mahoney et al., 2021: 568).

As mentioned, partly driven by my position as a student pursuing research-based degrees, a lot of my work was both individualised and highly time-bound. I was struck by the constraints of this, though found little to mitigate it during my Master studies in 2015/6, with very limited time for fieldwork. In aiming to mitigate this and avoid abandoning emergent connections, I selected the same focus and area of study for my PhD, and subsequently for my first postdoctoral position. While this did not always mean I could actively slow down, there were ways in which this meant I could spend slower time in the spaces I was researching, and develop familiarity and connections with the people that used these spaces. As I built this familiarity with people and spaces, I could increasingly guide my interviews according to local realities, focused on balancing questions around history, design, use, management, with those focused on methods emerging from first phases of research, with those targeted at the interviewees specific area of expertise and/or experience. Analysis was similarly built up iteratively, with manual coding conducted according to key themes that emerged from each phase of fieldwork.

One of the key tensions in these public spaces was the issue of homelessness, which shifted in severity depending largely on the nature of security and policing in each space (Middelmann, 2022a,b). Homelessness in Johannesburg has been driven by a complex mix of brutal, migrant-labour economies, unemployment, poverty, familial and health crises, and a lack of affordable accommodation, all exacerbated by prejudice and violent policing by both private and state actors (*ibid.*). Spaces controlled by private security representing local business interests were often quick to preclude or prevent homeless people settling, whereas in publicly owned and managed spaces (i.e., city departments, local police), homelessness was much more frequent (Middelmann, 2020). And yet, displacement and harassment by police remained very common, showing how circumstances faced by homeless people were disabling *and* debilitating. While homelessness did not start as my core research question, it demonstrated complex answers to two aspects of my investigation. Firstly, for my academic investigation, it revealed critical injustices regarding the interplay between design, history, management and use of public space, suggesting needs for holistic approaches to public space based on wider collaboration. Secondly, in terms of researching the public space of my hometown and my place in it, highlighting disconnection, inequalities and differences, relating to my positionality as a relatively wealthy, university based white researcher working in Johannesburg’s inner city, which is mostly black, largely relatively low-income.

This process of learning about the city and myself,³ in line with how my art practice was developing, provided ways of working through some of these inequalities and disjunctures by connecting aspects of my research with my life. Ethically, in conducting research on spatial injustice, I felt compelled to use my life and work, at least in

3 A paper with a focus on positionality, language, reflexive research methods, complicity and global inequality has been recently accepted for publication in another journal.



FIGURE 3

Drawing by author from 2016 during one of the first phases of public space fieldwork. The drawing evokes the early stages of becoming a member of the public, showing a disembodied self sending out signals to their surroundings. By being and knowing myself better in public space, I was working towards connecting with others. Sitting and drawing in public space as part of my research practice also evokes crip time—this was not active research in the sense of careful observation and intentional conversations/interviews—it was a case of an introverted, neurodivergent artist-researcher being and becoming themselves as an entry-point into the research process. A key connecting idea here is about cultivating authentic presence in public space, which I argue below is key to genuine connections and collaborative research and advocacy.

part, to work at addressing those injustices. As I deepened my research engagement with homelessness, including homeless people and various practitioners in the sector, I found opportunities to use my skills and insight to support their work. I began volunteering for the local and national homelessness networks as a researcher,⁴ which developed my understanding of homelessness and thus advancing research. Crucially, this manifested through improving and deepening my connection to people and the processes I was researching, expanding both my understanding as a researcher and impact as a person.

⁴ And later, as a treasurer. While this was not my main expertise, this was one of the needs of the community. Sidelineing my ego to some extent allowed me to contribute in this way.

3 Homelessness, disability and debility

This paper looks both at the intersection of disability and homelessness as well as looking at homelessness itself through a disability lens. I argue this helps reveal important characteristics and complexities of homelessness, which in turn has implications for understanding, researching and working with homelessness. Among several connections, disability studies shows how homelessness is itself disabling *and* debilitating because of the stigma, harassment, persecution, as well as exclusionary circumstances of society (Mashau and Mangoedi, 2015; Puar, 2017). Mashau and Mangoedi (2015) tie exclusion of homeless people to the history and reality of exclusion during colonialization, apartheid and xenophobia. Critical theory on disability studies—acknowledging complexities of the field, divergences of perspective, and multiplicity and heterogeneity of disability communities—has built on and with feminism, intersectionality, critical race and queer studies to help show that these

historical structures of oppression have played significant roles in shaping discrimination as it continues today (Goodley et al., 2019). Schalk (2022) is one recent example of a demonstration of the entanglement of oppressions, focusing as she does on racism and ableism and addressing these issues as connected which is critical for collective liberation. Evoking the importance of intersectionality, discussed more below, this paper builds on arguments to foreground intersectionality more explicitly in research, theory, praxis and advocacy relating to homelessness *and* disability.

One of the disabling impacts of homelessness involves chronic and often undiagnosed illnesses which are relatively common for homeless people. Exclusion faced by homeless people extends to healthcare systems, and is exacerbated by prejudice and discrimination. Furthermore, Mji (2006) shows in the South African context that homelessness makes people disproportionately prone to further disability, partly because of the denial of access to healthcare. Mji (2006: 355–56) points out that the ‘isolation, rejection and marginalization that comes with homelessness is compounded by disability’, noting the cyclical effects of exclusion which show how homelessness is also *debilitating*: ‘poverty makes people more vulnerable to disability, and disability reinforces and deepens poverty.’ Another example of the debilitating circumstances of homelessness that was common during my research in Johannesburg relates to requirements of bureaucratic documentation for accessing basic services and supports. It is exceptionally common for homeless people to be robbed by criminals, or have their belongings ‘confiscated’ by police, thereby exacerbating their denial of access. These multi-directional causal links between poverty, debility, and disability, linked to homelessness, have been noted in many other contexts, including Crawford (2013), warranting further comparative research. More specifically, mental health crises can be involved in causes of as well as being caused by homelessness (Padgett, 2020). Indeed, Martin (2022) has shown how under neoliberalism, people experiencing homelessness and madness are often irresponsibly conflated, highlighting the need for further research into their complex intersections. This speaks to expanding literature on how irresponsible deinstitutionalisation and lack of holistic mental health supports are directly involved in the growth of homelessness (Milaney et al., 2022).

Relatedly, writing like that by Lemus-Mogrovejo (2018) is part of a growing recognition of the intersectional impacts on people who are homeless and have other disabilities. While homelessness is disabling, and the way society treats disability makes disabled people more at risk of homelessness, intersectionality shows how people who are homeless *and* have other disabilities are especially marginalized, exacerbated by being racialized (also noting the impacts of heteronormativity, patriarchy, and other systems of domination and oppression). Intersectionality also helps demonstrate how disability and homelessness are both historically embedded experiences shaped by politics, economics and culture by emphasising how the entanglement of processes combine to produce oppression and marginalization in complex ways across differing contexts. This connects broadly to the strictures of life in neoliberal capitalism and ableism:

‘Neoliberal-ableism is the elision of national economic independence with an individual and cultural celebration of autonomy (Goodley, 2014) [which] ... associates happiness with self-reliance. Hence, while people with physical, sensory and

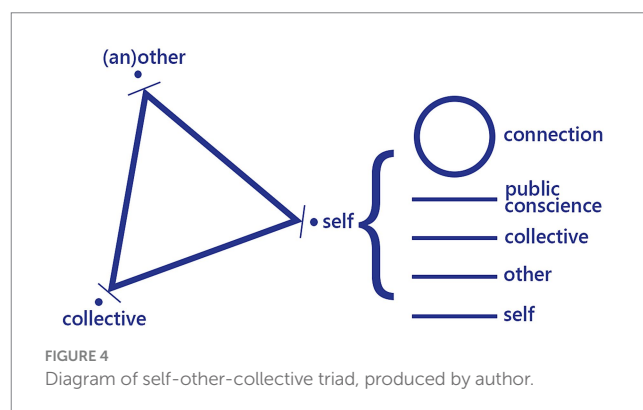
cognitive impairments risk experiencing disablism, all individuals of contemporary society are imperilled by the practices of ableism’ (Whitney et al., 2019: 1478.)

Nevertheless, while all are imperilled in these ways—constituting circumstances of widespread debility—intersectionality demonstrates how these constellations of forces impact people differently.

I have written elsewhere about practices and patterns of sharing by residents of Pieter Roos Park, where people exchanged goods and information in support of each other (author...). Mji (2006) discusses how disabled people in a homeless shelter came together around the idea that together challenges can be overcome, despite people having different priorities and challenges. Mji (2006) (*ibid.*: 355) goes on to describe some dynamics that evoke the importance of authentic connection and work across difference: ‘The value attached to interpersonal contact and support between homeless disabled people was matched with the importance accorded interpersonal contact and connection with able-bodied people who may or may not be homeless.’ This work is important in starting to show how homeless people and the issue of homelessness can teach us not only about how to research, but critical lessons on how to *be* as people.

4 Self/other/collective: public culture and the threshold of privacy

This section explores my attempts to remain open to how identities are formed and constituted mutually through interaction Erwin (2012), suggesting that these processes both reflect and shape public culture. This is demonstrated through a triad that signifies relationships between individuals, other individuals, and collectives (see Figure 4 below). Understood through this triad, and pursued through my research and artwork, I have tried to be open to how interlocking identities are constructed (and potentially transformed) through interactions in public space (Ruddick, 1996). Instead of approaching a conversation with ideas around who ‘I’ am and who ‘you’ are, I aimed at approaching a conversation as openly as possible, looking at the space between ‘you’ and ‘I’. Simone (2021: 1347) explores how this is necessarily open-ended: ‘Something is apportioned out to us as we apportion ourselves out to it, in a process of mutual figuring rather than the imposition of our intentions upon the objects or experience within the environment ... set against a backdrop where there could be many different alternative realizations.’



Landman (2019: 120) suggests that in South Africa, these dynamics are still rooted in the history of colonialism and apartheid, which created an “us” and “them” syndrome that is still prevalent.” This implies a long-term culture of disconnection and division in Johannesburg and other South African cities, connecting to growing polarisation globally (Carothers and O’Donohue, 2019) and to tensions within potential communities of care and wellbeing (e.g., Runswick-Cole, 2014). This necessitates inclusive politics to counter the neoliberal preoccupation ‘with defining and maintaining the borderlands between “us” and “them”’ which sustains polarization and excludes those not corresponding to the ‘ideal neoliberal type’ (Runswick-Cole, 2014: 1124, citing Ramlow, 2006). While South Africans are often guided into interactions in public places by prejudice and this public culture of disconnection, I have aimed to avoid predetermining the nature of the interaction and those it involves by focussing on the space in-between the self and another, which is where both ‘you’ and ‘I’ actually take their meanings in the moment. Notwithstanding moments where I have fallen into patterns of retreat, prejudice, or fear, focus on the threshold between public and private can bring new prospects for the relationships between selves and others starting from the micro-level (Whaley, 2018). This is the space where we work out who we are, who others are, and thus where publics are formed. Therefore, these moments are part of how public culture is shaped, reflecting Zukin’s (1995: 11) description of “[p]ublic culture as socially constructed on the micro-level.”

In my research methods and associated public art practices, I continue aiming towards reducing the boundary between self and other, between the internal and external worlds. Deepening this autoethnographic reflection and practice connects me with De Beer’s (2013: 1) exploration on connections and disconnections between the self, others, the university, the city, and its homeless residents: ‘carefully and deliberately seeking to hold on to different publics, seeking ways not to have to exchange one world of immersion for another, struggling between presence and absence, feeling slightly dismembered and trying to make sense of it’. My research and art are both important here, because without their intersection, these shifts would not have taken hold, at least not in these same ways. Many of course have developed more engaged, collaborative research practices without an associated art practice. However, my art practice and the ways it changed me have been central to these shifts, and the insights are relevant in other contexts, especially amidst calls for more community-engaged, social-impact oriented research. In exploring how to manifest this for myself, a core goal of mine is to develop an associated art and research practice that corresponds to de Certeau’s (1980/1984: 110) exploration of how spatial practice can incorporate ‘the joyful and silent experience of childhood; it is, in a place, *to be other and to move toward the other*’. This paper explores how this necessitates an apparent sacrifice of self, but one that allows a more authentic self to emerge in and through community.

A key learning from my fieldwork and art practice is that breaking down the barrier between self and other requires foregoing some private, internal space (ego). The boundaries between the self and others are permeable and blurred (Whaley, 2018). Following the assertion of this permeability, Whaley (2018) argues for a wider understanding of self, where the self can tend towards inclusion of others. I argue that Whaley’s (2018) reconceptualization of the self as inclusive, sacrificing some attachment to pure individuality, allows for the boundary between self and other to be reduced, which in turn opens space for the formation of collectives through a culture of

inclusion. This does not deny space for difference nor even contestation. In fact, Whaley (2018: 32) argues that in the context of a more inclusive vision of self, ‘[d]iversity and difference are understood not as threats or challenges but as vital sources of sustenance and enrichment.’ As such, the sacrifice of self is only apparent; one can become more fully oneself by connecting with others. While entering a public space as a researcher and outsider emphasised division, when I began entering public space to offer my art practice, one of my blessed gifts, I was able to be fully and authentically myself while also moving towards others.

Some of these moments, or interactions, are more revealing when looked at through the graphically represented symbolic relationship between the self, (an)other and the public, shown by the triangle on the diagram’s left side. The points on the triangle constantly shift and morph according to space, time, energy and actions. In other words, the shifting points of the triangle refer to connections, entanglements, and ‘transitions between the public and the private’ (Lefebvre, 1992/2004: 95). Despite each point remaining partly distinct from each other and the triangle, the self, others, and the public are necessarily mutually constitutive. The points connect directly in moments of interaction, which have a charged potential to shift the relationship between them. When the self and the other (self and another, or others) become closer towards each other, a wider public can become more concretely constituted, generating inclusion on a micro-level. This requires openness to and celebration of difference, which relates to a call by Mbembe (2018) to break down barriers between self and other, both practically and philosophically. When the self and others are pushed further apart (physically, spatially, emotionally, psychologically), formation of publics becomes more fractured and tenuous, allowing narrow interests to prevail. Whaley (2018: 30) argues that this fracturing often stems from fear and a view of the self and other as “mutually exclusive,” which can tend towards a public “culture of exclusion,” undermining both publicness and attempts towards spatial justice.

The right-hand part of the diagram disambiguates elements of the self, from the first pole of the self, the second pole representing another, the third pole of collectives, and the fourth of public conscience. The circle above shows that these different levels are connected for everyone, reminding us that the different levels, ourselves and others, are all part of the same whole. Importantly, the triangle is whole, demonstrating the reality of entanglement and mutual constitution between selves, others and collectives. Furthermore, implicit is the constellation of these relationships creating webs of interaction starting from all selves and constituting collectives through interpersonal contact. As written by de Certeau (1980/1984: xi), ‘each individual is a locus in which an incoherent (and often contradictory) plurality of such relational determinations interact’, noting how these ‘systems of operational combination ... also compose a “culture.”’ As people move towards and with one another, this culture becomes more public, more inclusive, and more supporting of communities of wellbeing.

Analysis through this triad aims to build on ‘disability studies scholarship today [which] shows how disability troubles normative concepts of self, other, agency, labor, property, and relationality’ (Kim et al., 2021). All three points on the diagram are entities, but each is entangled and overlapping with, and as such mutually constitutive of the other two. One cannot be a ‘self’ without there also being people who are not the ‘self’ but are ‘another’. Moreover, neither the self nor the other can exist without being part of a greater whole: a collective which corresponds to a/the public. This relates to the principle of *ubuntu*, ‘which some philosophers consider to be a quintessentially

African notion of interdependence ('a person is a person because of other people'). Ubuntu establishes clearly the virtue of care in its strongest sense' (Hassim, 2022: 60). This principle—in holding the 3 points on the diagram together—guided my attempts to break up the public-private binary during my research; our private spaces exist within public space. Our self (the smallest unit of private space) encounters all others (in their private spaces of the self) in space that is external to both the self and another: public space. There is a specific overlap and complexity here relating to homelessness in how private behaviours are forced into public space, creating a tense threshold between public and private. Erwin (2012) argues that these encounters, whether tending towards inclusion or exclusion, are where our individual identities are formed, implying that such encounters shape the formation (or potentially division) of publics and public culture. Thinking through my research in this manner correlated with attempts to bring my work and life closer together (Morreira, 2012).

5 Curiosity, art, advocacy: towards inclusive publics

I am grateful that I have found ways to make my research and art practice more outward-facing, connected, and engaged. While the way I frame and understand the triad suggests urges towards collaboration and connection across difference, critical disability theory and praxis of interdependence brings this all together. Interdependence and creative resilience/resourcefulness is also something that is central to disability studies and that I have observed in my research on homelessness. Interdependence requires adapting to the needs of others, i.e., moving the self towards others in the service of an inclusive public. Exploring the social model of disability through the lens of dementia, Milligan and Thomas (2016: 13, 14) speak about the importance of collaboration in understanding 'relationship between the individual and community ... understanding and valuing difference can only be resolved through the engagement of all involved.' Critical disability studies has done a lot of important work in shifting from individualisation towards solidarity and interdependence, with important lessons for researching and addressing homelessness by working across difference. In a review of Piepzn-Samarasinha's (2018) *Care Work*, Whiddington-Sadlowski (2023) articulates this shift: 'Instead of presenting her disability as an "illness that she overcame," she wrote about collective struggle and community building.'

Looking inward is part of the beginning of moving towards others. Important in driving this is curiosity, wonder, and play. Curiosity is linked to an appreciation of mystery that has been central to my art practice that aims to get deeply into the space of the unknown; 'to eliminate the unforeseen or expel it from calculation as an illegitimate accident and an obstacle to rationality is to interdict the possibility of a living and "mythical" practice of the city' (de Certeau, 1980/1984: 203). I argue, partly in following Paula Toledo, that this openness to mystery is related to an openness to difference which is foundational for collaboration. Toledo (2018) explores links between curiosity and openness to mystery, suggesting these as important bases for getting to know others from a place of compassion. Connecting strongly to the disability justice principle of 'meeting people where they are' (e.g., Choi, 2021), this compassion can in turn build connection, gratitude, and openness to wonder which keeps curiosity alive. This also links with the personal curiosities and connections that bring us into conducting research in any field or context. I argue that foregrounding these personal

connections more openly and honestly, rather than insisting on scientific objectivity, is important for practising more inclusive research, especially if considering research methodologies as part of developing inclusion more widely. An important dimension of the methodological implications of these arguments pertains to responsabilization of the individual, which is part of the individualism critiqued and explored earlier in this paper. The key idea here is that while this paper suggests internal shifts as part of the core of opening to inclusive publics, that the possibilities, especially for junior researchers in highly competitive, neoliberal institutions, are constrained by time-limits, funding requirements, expectation of continuous, high-level output. As such, a crucial avenue for future research is about how institutions and academia can change to accommodate these sorts of shifts.

Ultimately, my guiding impulse that resonates with artist and researcher Rosie Priest's (2020: unpaginated) call for collaborative practice across difference is to 'work collectively with the spaces of marginalization, not to erode them and bring them into the middle, but rather to celebrate and support, to explore and learn from' which necessitates 'long-term meaningful work with the communities whose voices, experiences and creativity have largely been neglected by the mainstream.' This kind of long-term work in research, spending open-ended time with people, connects to Riles's (2022 unpaginated) work on play and playfulness: 'Scholars need space for open, free form wondering and tinkering.' This playfulness and creative approach to life is a key link between my research and creative practices. Because there are multiple, inter-related, highly complex problems, creative collaboration is important in unearthing holistic solutions. Indeed, Schwan et al. (2018) have explored and worked with the power of art to support homeless youth in managing their stress, healing from trauma, telling their (otherwise often silenced) stories, and breaking down barriers with law enforcement and health authorities. Essentially, while my reflections on art, research and life are not intended as a necessarily replicable research tool, this type of work demonstrates how play, creativity, and art can be powerful in addressing complex, multi-layered issues that unsettle the distinction between work and life.

My art practice and advocacy work in the homelessness sector have generally not been an 'official' part of my academic research, not featuring in my research proposals, funding applications, or ethics procedures through the university; they were not directly part of my data collection that were analysed alongside observational, interview and other data. However, this is why the paper explores how research and life are related: because living my life and deepening connection to the research context has been an important process for my attempts at practicing inclusion and working for justice, *including in my research practice*. As such, this work at the edges of my research has played fundamental roles in shaping both my understanding of the research context and topic, and importantly in shaping my relationship with the issues I'm researching. This manifests through my art in moving myself and my praxis towards community, and in my advocacy through shifting my research from more extractive and individualistic, to more collaborative, action-oriented and activist.

Importantly, moving towards forming and sustaining inclusive collectives and publics does not fully address the tensions, domination and violence that can and does manifest between publics. As such, moving towards deeper and more inclusive forms of 'collective life ... does not obviate the ways collectives will need to deliberate and negotiate questions about what they want to be and how to live together.' (Simone, 2021: 1348). In working against the individualisation of neoliberal society, Nishida (2022) introduces the

idea of affective collectivity, which calls to centre human connection, solidarity and care. Further research is required about the relationships between collectives, how to address growing polarization, and beyond the shifts explored in this paper, what is required to develop a broader, mutual solidarity across various forms of difference. While this paper is limited by my mostly South Africa-based experience of researching homelessness and creative practice, it is informed by global and especially Canadian literature on homelessness and disability.⁵ This highlights the need for further research across contexts, linked to the need for research and action across difference and discipline, within and beyond the research context.

6 Conclusion

The paper largely focuses on the conditions under which we carry out our research methodologies, and the kinds of shifts that undergird methodologies that can support more inclusive publics and communities of care. Despite focusing on these political, spiritual, and ethical matters, some clear methodological implications also emerge. The importance of play is linked to curiosity, wonder, and openness—I argue that making time for creative, playful approaches as part of our methodological toolkits is important in foregrounding authentic relationships between researchers and participants. The issue of time for play extends to other aspects of the research process. Spending honest, open-ended time with people and in the context of research can deepen understanding and appreciation of multiple perspectives and complexity. In other words, slowing down, partly inspired by Piepzna-Samarasinha's (2019) “revolutionary slowness,” allows for greater reflexivity and expansive work across difference. Reflexivity is key to how internal shifts towards and with others can be better understood and consolidated, and for being more open and transparent about our reasons for and connections to research on the topics, themes or people we worth with.

In exploring the conditions and circumstances of research and associated methods, the paper uses a triad to examine the relationship of individuals (selves, private space) and others, exploring the implications of how these relationships constitute collectives (publics). To do so, in aiming to explore how this triad relates to research methodology, the paper uses two lenses. Firstly, the authors merging art and research practices as driving forms of curiosity, play, and openness to difference, including shifts towards homelessness advocacy beyond research practice. Secondly, using the lens of homelessness to explore aspects of these relationships in a research context, exploring how homeless people and others in the sector worked towards developing cross-cutting communities of care, and crucially working across difference. These are argued to be critical for broader, more inclusive publics and as such, communities of mutual support and wellbeing, as evidenced by realities of homelessness viewed through a critical disability lens. In contexts of inequality and researching marginalized groups, especially for relatively privileged researchers, openness about complicity in the conditions of

marginality and inequality is an important part of honest connection across difference.

Data availability statement

The datasets presented in this article are not readily available because the consent process did not make allowance for data to be shared outside of use by the researcher. Requests to access the datasets should be directed to Temba Middelmann, tjdm90@gmail.com.

Ethics statement

The studies involving humans were approved by University of the Witwatersrand Human Research Ethics Committee. The studies were conducted in accordance with the local legislation and institutional requirements. Written informed consent for participation in this study was provided by the participants' legal guardians/next of kin. Written informed consent was obtained from the individual(s) for the publication of any potentially identifiable images or data included in this article.

Author contributions

TM: Conceptualization, Formal analysis, Investigation, Methodology, Visualization, Writing – original draft, Writing – review & editing.

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Conflict of interest

The author declares that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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The author declare that no Gen AI was used in the creation of this manuscript.

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⁵ Noting that the author has been living and working in Canada since 2023. My experiences in these two contexts suggest resonance regarding the dynamics discussed in this paper, though further collaborative and comparative research is required.

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