CURRERE: EXPLORING DISORIENTATION & DISABILITY IN A TIME OF PANDEMIC[1]

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In December 2021, after my first semester of in-person teaching since the pandemic, I visited my doctor for what I thought would be a routine exam. Instead, my doctor found a tumor and arranged for me to be seen at the cancer center later that afternoon. Within 30 minutes of meeting an oncologist, I had an excisional biopsy. I canceled my evening classes but arrived the following day to teach for six hours. I taught mainly from my chair, unable to move without pain, but more unable or at least unwilling to stay home, worrying about my pending biopsy results.

While sitting in my office a few days later, my doctor called to tell me I had cancer. After more biopsies and a radical vulvectomy, I began immunotherapy. Because of COVID-19 protocols, I could not have anyone with me for my seven hours of appointments, lab work, and infusions that marked my first day of treatment. During those hours of reflecting and journaling, I thought a lot about my child's hospital experiences—my first experiences with PET scans, MRIs, CT scans, and even infusions were those of a mother supporting a child. As a cancer patient encountering similar tests and procedures, I have benefited from my child's willingness to share his knowledge and experiences. My child cautioned me about the discomfort of the IV during infusions and the need for candy and activities when sitting for long times. He warned me about the sounds of banging drums in the MRI, sounds made even more cacophonous because I requested Motown to be played during the tests.

While getting my scans and infusions, I recognized a familiar feeling of disorientation. Sarah Ahmed (2006) describes moments of disorientation as a "bodily feeling" that can "shatter one's sense of confidence in the ground or one's belief that the ground on which we reside can support the actions that make a life livable" (p. 157). The ontological function of such disorientation, according to Parrey (2016), is to "expose and leave us exposed to, the many, often strange, relations through which meaning and experience emerge" (para. 18).

In this paper, I utilize Pinar and Grumet's (1976) *currere* process to explore disability and disorientation during a pandemic. Specifically, I engage in the four phases of *currere*: remembering (regressive), reimagining (progressive), reorienting (analytic), and reacting (synthetic). Within this process, I will seek to understand my past experiences to situate myself in the present and imagine and work (collectively) to move toward a more just future.

REGRESSIVE PHASE: REMEMBERING

> *Campbell (2009), as cited by Parrey (2016), describes disorientation as "the lived experience of facing at least two directions: towards a home that has been lost ... and to a place that is not yet home" (p. 194).*

Sitting in the infusion room, my body (even more than my mind) remembered the feeling of anxiety in a hospital setting. I distinctly remember sitting in a hospital room with my just-turned-three-year-old child preparing for discharge after a four-day hospital stay. I felt anxious and afraid that I didn't have the skills to keep him safe during

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a seizure. In that first year, my orientation (ontologically) remained consistent—toward a home that I didn't yet recognize as lost or at least transformed.

It was not until I felt (more) confident in keeping my son safe and more focused on advocating for (and with) him in educational settings that disorientation occurred. I was disoriented because I had thought I was informed about disability and inclusive practices. I was in a Ph.D. program in curriculum studies, and I always (or at least usually) remembered to write "and disability" in a list of social identities and oppressive systems. But, in advocating for my child, I began to recognize the depth of my un-knowing, un-questioning, un-theoretical understanding of disability. While I had worked to develop pedagogical strategies to serve my students with learning disabilities, I had failed to question my epistemological and ontological assumptions about disability. In this way, disability was more than "unknown" to me; it was, as Campbell (2009) describes, "unthought" (p. 14). "Unthinkingly," I embraced a medical/deficit model—one in which I (as the teacher) would seek to "fix" my student by teaching how to use graphic organizers or checklists or allowing some choice in the representation of knowledge (see Goodley, 2014). My disorientation came as I contemplated my lack of theory and the harm I had done when I believed I was doing good.

During this experience, I sought out new theories and found Disability Studies, a multidisciplinary field that rejects the notion that disability is an individual problem. I discovered a social-political model of disability that identifies "the problem of disability … in built environments and social patterns that exclude or stigmatize particular kinds of bodies, minds, and ways of being" (Kafer, 2013, p. 6). Thinking with theory helped to ground me and help me move toward reorientation.

Progressive Phase: Reimagining

Recently, I was at my child's Individualized Education Program annual meeting. I was proud that my son presented a beautiful vision for his future; however, I was exhausted by the bureaucracy, deficit-centered labeling, and assumptions. Even though the meeting included a team of talented educators and we had technically gotten what we wanted, the conference felt painful because what we need is a better system. There is not a sense of urgency in creating something new.

In a speech to college students, Michael Dumas (2017) asked his audience to think about "25 years from now" (n.p.). He explained that

> you will be sitting here, and you will wonder what you have done to actually try to imagine that moment. If all you have done is think about what is practical and what people told you to think about, you will not get anywhere. (n.p.)

During the pandemic, I often thought about Dumas's words. About the value of dreaming and working toward a future that may seem impossible. Dumas's call to wonder, similar to Freire's imperative to "revive within ourselves our ontological capacity for dreaming" (Araūjo Freire, 2007, p. xvi), took on greater meaning.

I am not sure what disability justice looks like, but I know that visions of disability justice are more often seen through art and activism in community groups than in academic spaces. In *Care Work: Dreaming Disability Justice*, Piepzna-Samarasinha (2018) describes the struggle for social justice as "telling a story that is still being written" (pp. 167–168). This is beautiful and radical—the idea of writing a new story. I dream of a future where Universal Design for Learning is a given, a taken-for-granted baseline from which we build (Waitoller & Thorius, 2016). I imagine a school system where support services, untethered from damaging labels, are provided because they benefit children, not because parents with social, cultural, or professional capital know how to work the system (Harry, 2008; Ong-Dean, 2009). I envision a focus on culturally sustaining and inclusive practices instead of accommodations after the fact for children who aren't expected or welcome. I dream of collaboration between students, teachers, families, and leaders of disability justice movements striving to create more inclusive schools and communities (See Jarman & Kafer, 2014; Mingus, 2011). I contemplate conferences, annual meetings, and gatherings with virtual options so those valued members who cannot attend (because of disability/accessibility, or health crisis, or finances, or lack of childcare) can always be present because their presence is important to the community. As a parent, my dream includes building a world where young people can bring their whole selves to schools and communities without having to shield their spirits from ideologies entrenched in racism, ableism, and sexism.

Analysis Phase: Reorienting

> *Ryan Parrey (2016) argues that "Disorienting encounters put us—all of us—in touch with where we are (here and now) and what might unfold (the future), but they also put us in touch with how these encounters are each time (re)shaping the paths that led 'here' just as they shape the paths we follow 'there.'" (para. 2)*

I have now had eight treatments—I have at least seven more. In one of my journal entries following a challenging month of treatments and side effects, I wrote:

> I wish I could write a song about the overwhelming love I feel … since my diagnosis, but I am not a songwriter, and I cannot carry a tune. If I could sing, I would write about [my husband] waking early each morning to bring me coffee and care for my wounds. I would write a verse about my son, emotions always on his sleeve, calling me "cancer mom" and writing me poems, or my daughter making me the journal I am writing in and finishing a quilt we started when she was just a young child and presenting it to me after surgery. I would write about my mom and brother always being there to help and friends and family sending books, food, and love to let me know I am not alone. In prose, it sounds so mundane. If I could write a song, it would have faint sounds of sadness in the background, but chords of longing, of gratitude, of healing, and [of dreaming].

In the weeks and months after my diagnosis, I had a second experience of disorientation. I struggled to navigate my experience as a nondisabled scholar writing about illness while grappling with notions of ableism. I have consistently recognized that, in an ableist society, disability must be understood at least in part as socially constructed. But, it also became clear that there are, sometimes, embodied differences that cause pain or discomfort. As Wendell (2001) explains

> some unhealthy disabled people, as well as some healthy people with disabilities, experience physical or psychological burdens that no amount of social justice can eliminate. Therefore, some very much want to have their bodies cured, not as a substitute for curing ableism, but in addition to it. (p. 19).

During my treatments, I was frequently frustrated with my own body. This feeling of frustration made me remember an experience with my child. My then five-year-old son, growing up in a house filled with stories of disabled activists, poets, and scholars, asked me, "Is it ok that I don't like my seizures?" This question stopped me in mid-movement. I instantly understood that my effort to reframe disability in our home, combined with my (toxic) positivity created a barrier for my child to claim and express a range of emotions. I immediately apologized to my child, and we talked about all the things about seizures that made him frustrated, overwhelmed, and sad.

While I am still navigating my own experiences, I am grateful for my amazing team of doctors providing life-saving care and a community of activists and scholars providing the theoretical tools to frame my experiences (e.g., Clare, 2017). As a currently unhealthy woman without a disability, theories of disability and chronic illness (Wendell, 2001) have helped me frame my desire to heal from my cancer without feeling broken or at war with my body.

Analysis Phase II: Reorienting During the Pandemic

I was diagnosed with cancer during a pandemic. The pain of the pandemic to our larger communities is palpable—the loss of life, the struggles of isolation, the loss of learning for many children, the lack of resources for those impacted by illness or job loss, and the celebrations of re-turns to work/life/school as "normal" without acknowledging those for whom re-turn was not yet possible (or even desirable). Yet, healing and parenting through the pandemic also demonstrated glimpses of a more accessible future. In my home, I witnessed my son thrive with online learning. The new technology and skills developed during online learning benefited him even when most of his classmates returned to the classroom. While my daughter missed in-person school and friends, she found joy in cultivating new talents in her found time. As a teacher, I watched some of my students struggle and others thrive within a system of greater flexibility. While healing during a pandemic was lonely in some ways, the technologies popularized during the pandemic allowed me access to family and friends. As many disabled activists pointed out, things like working remotely or receiving care through telemedicine that were previously deemed infeasible were suddenly widely available. My third moment of disorientation came with the realization that we already had many tools needed to make a more accessible world. What is missing is a desire to create the spaces we need.

Synthetic Phase: Reacting

In this paper, I used the *currere* method, which Pinar (1975) describes as a way to "bracket the educational aspects of our taken-for-granted world" (p. 406) to analyze moments of disorientation (as in Petrina, 2014). I recognize that disorientation can help us question previous unexamined assumptions and dream differently. As I move toward re-acting, acting with new knowledge, new urgency, and a desire not to "return" to life as normal but to re-turn to a new way of living that centers access, justice, and belonging, I recognize that I do not need to fully know before I can act (in fact, such knowing would be impossible). I am committed to acting with urgency to create a more accessible future by parenting differently, teaching differently, healing differently, and thinking collectively.

I will end by sharing that writing this essay has been valuable to me, but I am uncertain if it is helpful for you to read. Yet, I am sharing my experience with those of you reading this essay, even though sharing made me feel vulnerable and uncertain, because I hope that if we begin to share both our vulnerabilities and our imaginings, we may be able to dream more, and in collective dreaming, we may free ourselves to build something new and better. We may be able to move in the direction of more just and accessible "homes" and schools and communities. I hope that we might dream a new vision and that, 25 years from now, we (or those who come after) will see that vision enacted and feel empowered to dream things we cannot yet imagine.

Postscript

I presented an earlier version of this essay at the *Bergamo Conference on Curriculum Theory and Classroom Practice* with two of my scholar-friends, Jamie and Sandra. After our presentation, I went with my colleagues to the cafeteria, where I got lightheaded—a physical disorientation that is a side effect of a now chronic condition caused by treatment. Without a word, my friend Jamie caught my arm, carried my tray, and helped me sit down. I immediately apologized for my body, my weakness, and the changes I was experiencing. Even while theorizing with disability studies, deficit thinking and guilt crept into my social interaction. Essays sometimes make our experiences seem reconciled, but our experiences are messy. While filled with moments of insight, I recognize disorientation can also look like trying to push aside feelings of shame while being uplifted by a community that embodies an ethic of disability justice and care.

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Endnotes

[1] The *currere* process is, by nature, autobiographical. Because our lives are entangled with those with whom we make a life, my story is not just mine. I have shared this work with family members named in the piece, and they have (graciously) allowed me to share. However, I acknowledge that, if they were writing their memories of the same events, they would have differences in recollection, emphasis, and analysis.