Illness, Madness, and Disability



# MEMORY SEEKING: MAD PHENOMENOLOGY AS ORIENTATION

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What if story was homecoming?
—Aurora Levins Morales, *Kindling* 

Disability is not simply a physical affair for us; it is our ontology, a condition of our being in the world.

—Robert F. Murphy, *The Body Silent* 

#### SOMATIC OPENING ONE

My body speaks to me. My body remembers the stories I cannot access. This is what S. Kay Toombs calls the "living of experience," what Gabriele M. Schwab names "the memories of the body and its somatic enactment" (1992, xi-xvi; 2010, 2). Somatic enactment, "somatic existence": a culmination of unnamable things. I am always narrative, here; I am always porous (Schwab 2010, 2). In these moments, my body repeats and somatic story-tells through sensation: nausea in my chest that tug-crawls upward toward my throat, the feeling of being far, far away.

Bodymind. I write these words as a phrase to remember. My body is not the only medium through which I access and engage with the world. My mad bodymind directs much of my journeying, impacting how I relate to my body, my presence, how I process and feel. For over eighteen years, the experiences I have had with madness have dictated how I, to use

<sup>&</sup>lt;sup>1</sup> Informed by Mad Studies and mad activism, "mad" is a term that some folks with psychiatric disabilities use to name themselves, as opposed to using language like "mental illness" or "mental disorder." Mad as an identity term also has political roots.

Shayda Kafai Memory Seeking • 28

Toombs's language, "exist or *live* my body" (1995, 11). As a mad border body, a dual traveler, someone who exists in the borderlands of madness/sanity, I engage with the world in a fluid way (Kafai 2012). Deterioration and wreckage shape-shift into rootedness and balance, back to the chaotic, back to the placid. These somatic enactments can occur in the same hour or in the same day. Sometimes, still, my mad bodymind is consistent and tranquil; my bodymind is abundance, is respite. Mad phenomenology offers me a language to name my bodymind's experiences as mad, as in search of orientation. This is mad narrative. This is mad phenomenology, an incongruent way of "being-in-the-world" (Toombs 1995, 3). These are the diverse renderings of "being-disabled-in-the-world" (Diedrich 2010, 210).<sup>2</sup>

## **SOMATIC OPENING TWO**

There are large parts of my childhood that I cannot remember. Looking back now, I can identify years with colors and sensations; there is no language, no specificity. I am six, or maybe ten—gaps exist even here in the retelling—and something has happened to my body. I feel the colors green and yellow. I sit in the sun now to remember, to ground myself in the tangible. I walk barefoot in the yard by the vegetables that are trying to grow in this heat. I am barefoot to feel. I stand on pebbles and still this history is inaccessible.

Mad phenomenology is not singular. It is expansive, networks that are unique in their expressions. Mad phenomenology orients us, the mad many, as we move through our lives; it orients our experiences, the remembering, and the forgetting. This phenomenological framework reminds me that my body informs my mind, that my mind informs my body, and that my experience of madness and how I am in the world is an integration of the two. Mad phenomenology empowers me with fluctuations and diverse pathways, places where my bodymind is not regulated by the madness/sanity binary.

Mad phenomenology reminds us of the toxic and fictional renderings of "normalcy"; it helps us push back against the standardization of nondisabled supremacy, of neurotypicality. I stretch-pull this lens to understand how the narrative of madness—how naming it and acknowledging it gives us the opportunity to move away from stigma. Beyond the medical industrial complex and its language of diagnosis, mad phenomenology creates past the singular, rigid mad narrative: madness as an error or defect to fix, madness as an interruption to living, madness as a highly gendered and racialized experience.<sup>3</sup>

<sup>&</sup>lt;sup>2</sup> Diedrich stresses that she is not using disability here as a "universalizing sign," but instead as a heterogenous identity category with unique, diverse experiences (2001, 210). I use the term here with the same logic.

<sup>&</sup>lt;sup>3</sup> Similar to other disabled folks, I know that my relationship with the medical industrial complex exists in a place of duality: I must continue to critique the medical industrial complex while also relying upon it to survive.

Shayda Kafai Memory Seeking • 29

In this new space, I am person, I am process, I am bodymind. Mad phenomenology ensures I bear witness without judgment to the reality that my mad bodymind *needs*. This mad "vehicle for seeing" pushes me past the shame that often overrides my mad agency. To "live my body[mind]," I need more than eight hours of sleep (Toombs 1995, 10). I need slowness. I need to take loving breaks and sit in the sun. I need therapy and medication. I need. My lived mad bodymind helps me unsettle the importance of phrases like "I should . . ." and "I cannot . . . ." My mad phenomenology teaches me about a reality based in bodymind inquiry; the bodymind becomes a tool (Thomas and Longden 2015). Here, I look inward. My mad bodymind informs what each day requires: the pacing, the levels of interaction, what I can focus on, what I can do.

### **SOMATIC OPENING THREE**

My lack of memory disconnects me from my bodymind. I float-shift through time. I am paused; I am distanced. The bathtub is where I go to feel again, to feel through. Gravity reminds me of my tangibility every time I lift myself from the water. I stand, each time astonished: I am a "being-in-the-world" (Toombs 1995, 3). This lifting brings me home to the stories remembered and the stories lost. Here, I am made familiar to myself, once again.

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