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### Modeling Disability: Softly Making the Invisible Visible

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# **MODELING DISABILITY:**

Softly Making the Invisible Visible

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BFA in Studio Art

Washington University in St. Louis

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1 May 2020

## Abstract

“I am not asking for pity. I am telling you about my disability.” -Eli Clare<sup>1</sup>

In the following Bachelor of Fine Arts thesis statement, you will not find someone overcoming their disability. You will not find a tale of inspiration. You will not find a cure for ableism.<sup>2</sup> You simply will find an individual's experience of disability— my experience of disability.

My invisible disability puts the medical model and social model of disability in constant tension as I navigate everyday life living with Chronic Fatigue Syndrome and severe arthritis. Both models seek to find blame for disability, whether in searching for a medical cure for illness or putting blame on society at large for creating barriers. Instead of abiding by these limiting models, I cope with disability in my own way. I embrace the contradictory notion of having significant physical limitations while giving into the pressures of our capitalist society to physically produce. I make my own models through accepting my identity and embracing the human-like, huggability of soft sculpture. As a sculptor, I do not need to find blame through theoretical models of disability. Instead, I make literal models representing my lived experience. I turn my invisible, private experiences into visible, public ones.

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<sup>1</sup> Eli Clare, *Exile and Pride* (Duke University Press, 2015), 7.

<sup>2</sup> Ableism is discrimination against disabled people. It posits that able bodied people are superior to disabled people.

Disclaimer: The following describes my experience living with an invisible disability. I do not speak for the entire disability community. I hope to represent my individual experience wholly and honestly. I want to create much needed dialogue and visibility. As Audre Lorde said in her *Cancer Journals*, “For silence and invisibility go hand in hand with powerlessness.”<sup>3</sup>

When I walk through an art exhibition, unfortunately, I am not looking at the art. I am looking for a place to sit. As an artist, I face unrelenting inner turmoil. I want to get lost in a painting. I want to weave in and out of an installation until I understand how the artist made it. I desperately want to give each piece the attention I hope viewers will give my own work. Yet, there is the nagging thought at the forefront of my brain— when can I sit down?

Other visitors mill around the exhibition space. If they glance my way, they see a twenty something year-old woman sporting quirky glasses and paint-dusted velcro sneakers. They see me look quickly at a piece and move on to the next one. They see me skipping works of art. They do *not* see my desire to see everything while trying to leave the space so I can rest. They do *not* see me resisting the urge to hug my body in hopes that the pain will subside long enough so I can experience all the artworld has to offer. I am struggling, but if the other art viewers do not see my struggle, does it exist?

There is an unsaid irony to being a visual artist with an invisible disability. The world is a visual place and the artworld prioritizes visibility over everything. Art literally depends on having “viewers.” Does art even exist if we cannot see it? The concept of being seen to be believed rules the artworld. My disability directly contradicts this notion. But, visibility becomes

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<sup>3</sup>Audre Lord, *The Cancer Journals*, (San Francisco: Aunt Lute Books, 1997), 40.

my own medium to manipulate. I make my invisibility visible. I contradict the medical and social models of disability. I do not seek to set blame for my disability. I search to visually claim the invisible. I work within, through, past, and against the limits of my disabled body while I navigate an able bodied world.

There are multiple models of disability, including the medical and social models. The medical model views disability as strictly a medical condition and searches for a cure. Ignoring disability as a social identity category, it implies that anyone who is disabled is sick. Relating this model to my disability is complex, because technically speaking I am sick. I have Chronic Fatigue Syndrome (CFS)<sup>4</sup> and severe arthritis along with a conglomerate of other minor health issues. “Illness” and “health issues” imply that I have a sickness and am in need of a cure. However, my disability consists of non-curable illnesses. The medical model acknowledges the origins of my disability while ignoring how I codify it in everyday life.

By focusing so heavily on medicine and cure, the medical model ignores my disability’s positive impact on my life. I am not grateful for the painful symptoms or the days when I am physically unable to move, but I am thankful for the distinct perspective on the world my disability has given me. If I were magically cured tomorrow, the lessons I have learned from being disabled, the experiences of ableism, discrimination, and intolerance, and the knowledge that people’s pain is not visible would not disappear. My experiences and identity will forever be bound to my disability. It has given me as much as it has taken from me. Explaining her relationship with Myalgic Encephalomyelitis (ME), another term for CFS, disability scholar Susan Wendell states, “I cannot wish that I had never contracted ME, because it has made me a

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<sup>4</sup> a chronic illness associated with inescapable fatigue and post-exertional malaise

different person, a person I am glad to be, would not want to have missed being, and could not imagine relinquishing, even if I was ‘cured.’”<sup>5</sup>

Living within the identity category of disability, even when painful and invisible, does not mean constantly searching for a cure. It means reforming one’s identity and life into something more. My *Pill Bottles* further exemplify this concept. Their empty interiors have a contradictory, two-fold meaning of hope and hopelessness. Emptiness means unlimited possibilities. It means the conditions written on the outside do not limit the potential of what could go inside. Even more poignant is the message of hopelessness. A typical pill bottle serves as a vessel storing curative medication. An empty pill bottle with no trace of ever being filled is ominous. It dictates that there is no cure. This message only threatens someone who strictly



Figure 1. Libby Evan, *Pill Bottles*, nylon, cotton, poly-fil, cardboard, serving platters, 23" x 50" (per bottle), 2020.

<sup>5</sup> Susan Wendell, *Rejected Body: Feminist Philosophical Reflections on Disability* (New York: Routledge, 1996), 83, quoted in Allison Kafer, *Feminist Queer Crip* (Indiana: Indiana University Press, 2013), 43.

abides by the medical model of disability, but an expansion of how we view disability demonstrates that a lack of cure does not equate to a lack of a full life.

The social model believes societal barriers cause disability and without them disability would not exist. For example, a building with stairs but no ramps or elevators would disable a wheelchair user from using that space. While this model is more disability positive, because it blames societal constructs instead of blaming non-curable bodies, it is also deeply flawed. Why does my identity need a source of blame in the first place? According to Allison Kafer, my disability disrupts the social model's logic. Societal barriers impact chronically ill bodies differently than how they affect other disabled bodies. In her book, *Feminist Queer Crip*, Kafer references the social model and through acknowledging chronic pain and illness, she delves into the social model's flaws. Kafer writes, "social and structural changes will do little to make one's joints stop aching or alleviate back pain. Nor will change in architecture and attitude heal diabetes or cancer or fatigue. Focusing exclusively on disabling barriers, as a strict social model seems to do, renders pain and fatigue irrelevant to the project of disability politics."<sup>6</sup> When disability lies in the interior of the body, it complicates the social model.

While I am thankful Kafer acknowledges chronic illnesses as a disability category, she fails to mention that I live on a barter system. Environmental barriers deeply impact that system.

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<sup>6</sup>Allison Kafer, *Feminist Queer Crip* (Indiana: Indiana University Press, 7.

Technically, I can take the stairs to my basement studio. I am physically capable of doing so but on an arthritic flare day the stairs become an impossible environmental barrier. On a day when my pain stays at a manageable level, the stairs still pose a threat to my ever waning energy level. If I take the stairs today, I will not be able to take them tomorrow and might not be able to get out of bed tomorrow. Every use of energy means unpredictably sacrificing something tomorrow.



Figure 2. Libby Evan, *Impossible Stairs*, chiffon wooden dowels, embroidery floss, prints on paper, 6.5' x 3.2', 2019.

*Impossible Stairs* reflects my lifelong bartering. The chiffon stairs dangle precariously from the ceiling. They swing forever in and out of reach. If I finally am able to jump on the first step of my chiffon stairs, they will fall. The stairs cannot support my weight thus reflecting how the decision to take stairs puts an unmovable weight on my psyche. I cannot simply take the stairs. Stairs dangle and sway in the forefront of my mind as I decide once again to take the elevator.

No matter what each model of disability posits, having an invisible disability means carrying a burden of proof wherever I go.

Disability scholars question if coming out as

disabled means accepting one's true identity of being disabled or if it means explaining one's



disability to others?<sup>7</sup> I believe coming out is a two part process. First, I have to accept that I am disabled. Secondly, I have to reveal my disability to others. In “MY BODY, MY CLOSET,” Ellen Samuels references Deborah Peifer’s experience of invisible disability in which she used a white cane she did not need in order to signal her eye condition and avoid constant verbal disclosure.<sup>8</sup> Like Peifer, I cannot keep verbally coming out to the world. Verbally dictating my entire medical history to someone just so they begin to hold a fleeting modicum of understanding is not worth it.

Instead of verbalizing, I visualize my disability through sculpture. *No Longer Invisible* is an eighty-one inch long version of my handicap placard made of hand embroidered bubble wrap. The sacrifice of my arthritic hands painfully weaving embroidery floss through bubble wrap for eight hours at a time was worth it. I celebrate and depend on my handicap placard— my needed white cane. It serves as a nonverbal

coming out label. Yet, it does not disclose my exact disability. My arthritis adds extra dimension to *No Longer Invisible*. This piece demonstrates the hidden fight between my will to produce



Figure 3. Libby Evan, *No Longer Invisible*, bubble wrap and embroidery floss, 33” x 81” x 1” 2020.

<sup>7</sup> Ellen Samuels, “MY BODY, MY CLOSET: Invisible Disability and the Limits of Coming-Out Discourse,” *GLQ: A Journal of Lesbian and Gay Studies* 9, no. 1-2 (January 2003):237-9.

<sup>8</sup> Samuels, 241.

work and my physical limits. The intense, tedious labor of embroidering caused several flare ups and bed ridden days which people cannot see when they look at this piece. Even though I successfully completed this sculpture, I have not overcome my disability. Instead, I have learned how to live with and within it. Simply put, I have come out.

Similarly, Yvonne Rainer recreated an able-bodied performance and transformed it into *Convalescent Dance*. In this new performance, she put “her ailing body on stage,”<sup>9</sup> as she danced in a bodily state of disability. Illness altered Rainer’s movements but not everyone understood how her body’s limitations altered her performance. One critic referred to her movements as “wistful” while another critic criticized the first critic for not acknowledging Rainer being in the “throes of recovery.”<sup>10</sup> A third critic resolved the argument. They said Rainer’s performance suggests “the limit of what one can know of another body by way of kinesthetic empathy.”<sup>11</sup> As Rainer’s piece articulates, art about disability does not need to reside on full disclosure but rather can have a secret underbelly that only a partial audience will understand. For even when one fully discloses their disability, few people will attempt to understand, empathize, and accommodate.

Unlike Rainer, I do not use my disabled body as a medium, but I still refer to my “ailing body” through soft sculpture. Soft sculpture is undeniably bodily while depriving objects of their functionality. This unique medium celebrates my disability while allowing me to simultaneously embrace and challenge my physical limitations. Sewing is how I create structure within sculpture while accepting some of my limits. Beyond its utilitarian and accommodating nature, soft

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<sup>9</sup> Risa Puleo, “Sitting Beside Yvonne Rainer’s *Convalescent Dance*.” *Art Papers* 42, no. 4 (2018-2019): 10.

<sup>10</sup> Puleo, 10.

<sup>11</sup> Puleo, 10

sculpture has an inherent lopsidedness and huggability. Its body-like visual irregularities are comforting yet indescribably sad. It sits on the line of humor and melancholy.

Claes Oldenburg is synonymous with soft sculpture. Oldenburg's *Floor Burger* fits its title as he translated a burger into a large soft sculpture which sits on the floor. In reference to *Floor Burger*, Nadja Rottner writes, "Soft sculpture employs a formal deformation of scale and



Figure 4. Claes Oldenburg, *Floor Burger*, acrylic on canvas filled with foam rubber and cardboard boxes, 52" x 84", 1962.

physicality that catapults the object out of normal relations with human scale and, simultaneously, relies on the effect of pliable softness to shrink distance and pull the object back into the realm of the human body."<sup>12</sup> While typically oversized, this medium remains formally relatable enough to be approachable. Rottner also accurately states, soft sculpture "has often been viewed as anthropomorphic because it evokes the image of the human body (or parts of it) and creates an uncanny feeling of dead organicity come 'alive.'"<sup>13</sup> This form of sculpture creates cognitive dissonance. Viewers know it represents objects but somehow they seem human and alive. Yet, soft sculpture does not appear or pretend to be functional. Oldenburg's *Floor Burger*

<sup>12</sup> Nadja Rottner. "Object Lessons," *Claes Oldenburg* (Cambridge, MA: MIT Press, 2012) 180.

<sup>13</sup> Rottner, 181

is not edible and therefore cannot meet a burger's intended function. My *Pill Bottles* are lumpy, lopsided, saggy, and barely have the ability to stand. They do not hold pills. They are not pocket sized or convenient. They seem to be at odds with gravity. They have limitations in ability. They are their own disabled bodies.



Figure 5. Libby Evan, *Pill Bottles*, nylon, cotton, poly-fil, cardboard, serving platters, 23" x 50" (per bottle), 2020.

Rottner rightfully connects soft sculpture to human quirks but she fails to mention another important connection soft sculpture holds. Soft sculpture is materially tied to the bed. One could even describe it as large, oddly shaped pillows. Like soft sculpture, the bed is a source of comfort, but, in my experience, the bed is also a source of dependence. Living with a fatigue related condition makes the reference to the bed and pillows relevant to my work. *Pill-ows* is a pile of over one hundred pill-shaped pillows. The child-like and youthful patterns indicate the dependent relationships that having a disability creates. When my symptoms were severe, at age





Figure 6. Libby Evan, *Pill-ows*, 106 individually crafted items, 32" x 48" x 40", 2018.

eighteen, my mother lifted me out of bed and dressed me. I was back to the state of toddlerdom. *Pill-ows* also insinuates my dependence on medication. They mirror the capsule shapes that I swallow daily in order to get out of bed. Despite this darker context, *Pill-ows* still holds the “formal deformailization

of scale and physicality”<sup>14</sup> of soft sculpture while providing the comfort of the bed.

In direct contrast, Mona Hatoum’s object-based practice of hard, cold, and metal objects also references dependence and the body. She constructs empty furniture, objects, and installations which only the body can fill. Tamar Garb writes about her practice, “implements become weapons and furniture serves to confine, punish, and betray the body rather than support it. Strangely empty and devoid of human presence, Hatoum’s furniture based pieces nevertheless invoke the absent body.”<sup>15</sup> Hatoum’s metal wheelchair has handles made of



Figure 7. Mona Hatoum, *Untitled (Wheelchair)*, stainless steel and rubber, 38" x 20" x 33", 1998.

<sup>14</sup> Rottner, 180.

<sup>15</sup> Mona Hatoum and Cristina Zelich, *Mona Hatoum* (Salamanca: Centro de Arte 2002).

knives. Anyone who pushes the chair will bleed. Viewers can conclude that being someone else's caretaker means slicing one's hands with a proverbial, and in Hatoum's case, literal knife. Conversely, having a disabled body and depending on someone else means hurting that person. Hatoum disrupts functions of objects the same way soft sculpture does but her disruptions have very different bodily reactions. Viewers have to resist the urge to jump into my pile of *Pill-ows* while they recoil from the potential injury Hatoum's wheelchair will cause.

Also contrasting *Pill-ows*, Beverly Fishman's *Pill Spill* features over one hundred glass



Figure 8. Beverly Fishman, *Pill Spill*, Blown glass, over 100 unique elements, feature at Toledo Museum of Art, 2011.

pill capsules sprawled on the floor of the Toledo Museum of Art. The formation of Fishman's pills and their hardness create a different viewer-pill relationship than *Pill-ows*. Their hardness makes them less bodily and more object-like. In designing their formation, Fishman says, "I

immediately thought about treating the museum as a 'body' and releasing my capsules into the curved glass hollows between its walls, transforming the building's architecture into a giant circulatory system."<sup>16</sup> By turning architecture into the body's interior, Fishman focuses on the body's biological relationship with pills while I focus more on the psychological. In describing Fishman's pill related art practice, Bonnie Pitman states that Fishman turned "from disease to

<sup>16</sup> Bonnie Pitman, "Pharma Art—Abstract Medication in the Work of Beverly Fishman," *JAMA* 319, no. 4 (2018): 327.

cure,”<sup>17</sup> therefore it seems Fishman’s work resides in the medical model. My work does not reside in a specific model of disability. Instead, I search for my own model.

As I model disability through sculpture, each piece inherently addresses the tension between production and disability. In his seminal work, *Crip Theory*, Robert McRuer writes, “in the emergent industrial capitalist system, free to sell one’s labor but not free to do anything else effectively meant free to have an able body but not particularly free to have anything else.”<sup>18</sup> Capitalist society expects all bodies to be able to produce goods. Disabled bodies contrast this norm. As the traveling exhibition “Sick Time, Sleepy Time, Crip Time: Against Capitalism’s Temporal Bullying” notes, living with chronic illnesses means operating on a timeline that may not be conducive to the pressures of constant production.<sup>19</sup> I fulfill the societal expectation to produce. Still, while it seems I constantly work in my studio, what remains unseen are the days when I cannot move and am bedridden. What stays hidden are the silent tears I have shed as I ignore my body’s pain signals to finish a project by its due date.

My unescapable urge to create also stays hidden. While painful and sometimes seemingly impossible, the physical act of making keeps my body in motion. Since I experience severe full body aches and exhaustion so deep it feels like it is embedded in my bones, I need a worthy reason to force my body to transition from the restful position of my bed to anywhere else. Making is that reason. But, I still cannot ignore my bartering system. I force myself to ration energy. Kafer writes, “This idea of conserving energy, of anticipating... bucks the American

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<sup>17</sup> Pittman, 326.

<sup>18</sup> Robert McRuer, *Crip Theory: Cultural Signs of Queerness and Disability*, (New York: New York University Press, 2006), 8.

<sup>19</sup> Taraneh Fazeli, “Notes for ‘Sick Time, Sleepy Time, Crip Time: Against Capitalism’s Temporal Bullying’ in Conversation with the Canaries,” *Temporary Art Review*, December 8, 2017.

ideal of productivity at all costs, of sacrificing one's body for work."<sup>20</sup> I do in fact sacrifice my body for my work but I do so because ironically it keeps my body functioning. I live in constant fear that the second I stop pushing myself to create is when I will finally give in completely to my pain and fatigue. I fear I will never recover. If the American ideal surrounds being able-bodied, then my very identity of being a chronically ill artist with a physically challenging practice surpasses, succumbs, and fails to submit to the ideal.

The pharmacy name on my *Pill Bottles* is *Wilting*. In reference to a plant, to wilt means to "become limp through heat, loss of water, or disease; droop."<sup>21</sup> I am the plant. I have literally limped due to illness. I have once stood temporarily able bodied and have had to sit down minutes later as my body began to droop. Unlike the plant, I always return to my erect position even if just for a fleeting moment. There is indeed an unsaid irony to being a visual artist with an invisible disability but that very irony has spurred my creative practice. My creative practice gives my wilting body a reason to manage to wilt and produce simultaneously. I do not seek a cure. I hesitantly thank medical interventions, especially pills, because they give me the boost of function on which I depend. I do not blame the environment for creating my disability. While universal design and ending ableist attitudes would deeply benefit my life, they would not take away my physical pain. Being a chronically ill, disabled artist means seeing the invisible. It means creating tools to allow others to see it too. It means doing everything I can to find ways to model my disability experience without garnering pity but instead cultivating understanding. There is no model of disability that could ever fully encapsulate my disability experience, but my soft sculpture *Pill Bottles* are the closest I will ever get to finding or creating that model.

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<sup>20</sup> Kafer, 39.

<sup>21</sup> "Wilt: Definition of Wilt by Lexico," Lexico Dictionaries | English, Lexico Dictionaries.





Figure 9. Libby Evan, *Pill Bottles*, nylon, cotton, poly-fil, cardboard, serving platters, 23" x 50" (per bottle), 2020.

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