

Shatter Not the Branches of the Tree of Anger: Mothering, Affect, and Disability

SUSAN L. GABEL 

Using the social interpretation of disability, Foucault's theory of disciplinary power, literary devices, and feminist literature, I write an affective narrative of mothering disabled children. In doing so I illustrate the ways in which the materiality of normalcy, surveillance, and embodiment can produce emotions that create docile mothers ashamed of their contribution to the world, conflicted mothers struggling with dissonant affects, and unruly, angry mothers battling against the architectures of their children's oppression.

PRELUDE

I want to write a personal narrative about affect and mothering disabled children¹ but I find it difficult for many reasons. First, one story cannot capture the complexities, joys, sorrows, pride, and guilt associated with mothering any child, so I must trust my reader to understand this as a story about one aspect of mothering, what Adrienne Rich calls its “exquisite suffering” (Rich 1979, 21). Second, I identify as disabled, but I am privileged in many ways and not ready to explore that aspect of mothering at this time. In addition, I feel protective of my children, although they are adults. Much of what I write intersects with their stories, but I will not ask them for permission to appropriate their stories.² From my perspective, my adult children need physical, cognitive, and emotional support twenty-four hours a day every day. They have what I call “significant support needs” similar to Eva Feder Kittay’s description of her daughter’s support needs (Kittay 1999).

Due to my focus on shame and disability in mothering, I risk being misunderstood as representing disabled people as abject and pitiable, caught in a web of humiliation. Do not misconstrue my story as a story about my children. They lead significant and dignified lives despite their experiences with ableism. Nor is this a story about disabled people. I work with the assumption that “disabled people are *not* the subject matter of the social interpretation of disability” (Finkelstein 2001, 1). In using the social interpretation of disability, often referred to as the social model of disability, my body of work focuses on the social, economic, and political barriers that disable

individuals with devalued embodied differences (for example, impairments, medical conditions) and prevent them from full inclusion in all aspects of society. Disability is my focus, not disabled people, although it can be impossible to write about disability without referring to disabled people, which at times I do here. Using Finkelstein's logic, this story is about the ways in which the structural oppression re/producing disability, or ableism, is experienced affectively by me as a mother of disabled children.

I use "mothering" to represent the embodied experience of nurturing and raising children. Mothering is situated within the institution of motherhood and numerous other structures or institutions (for example, class, race, marriage, patriarchy). My experience of mothering also is grounded in ableism. I use "mother" as a subject position, a locus point in power networks (DiQuinzio 1993) that associate motherhood with socially valued children (Laviani 2011, 278; Gabel and Kotel 2015). To bridge motherhood as institution with mothering as my embodied experience, I use Michel Foucault's theory of disciplinary power rendering mothers like me isolated by the normative discourses of motherhood (Foucault 1977; Gabel and Kotel 2015) and emotionally pliable via the strategies, or micro-physics, of power (Foucault 1982; Lieb 2017) operating in personal space, guiding individual conduct (Foucault 1991), and authorizing or denying emotions.

Shame, for example, is authorized and proscribed by power. Simply understood, shame is "a sense of failure to attain some ideal state" related to one's "whole self, rather than to a specific act of the self" (Nussbaum 2006, 184), thus it can be painful to feel shame. It can lead to a loss of dignity and equal status (Brooks 2008) and is associated with a low sense of self-worth (Galligan 2014). According to Eve Kosofsky Sedgwick, "shame attaches to and sharpens a sense of *what* one is" (Sedgwick 2003, 37; emphasis added) or who one is rather than what one does (Gilbert 2003). Shame effectively silences and marginalizes the one feeling shame (Leeming and Boyle 2013). Women may be more prone to shame due to their gendered and subordinated social position (Bartky 1990; Lyerly 2006). More specifically, Anne Lyerly argues that women are situated within social spheres that reinforce women's shame and their impotence as embodied individuals (Lyerly 2006). In particular, women can feel shame when their sense of themselves as mothers differs from their visions of the ideal mother (Brooks 2008).

The above statements suggest shame is a static affect situated within gendered and cultural norms, but shame can be generative and productive of anger, which I experience as shame's antithesis. Shame silences. Anger clamors. Shame paralyzes. Anger agitates. First, however, shame silences. This is my starting point, but it is a difficult point from which to begin. How does a mother break her silence? She begins with other people's stories by saying, "I have a friend who"

AND SO I BEGIN

For many years my Story has asked to be told, but I kept pushing it away. We struggle, my Story and I, and I say "Not now. I have other priorities." I think I need time to heal

because my wounds are too raw. “Now,” says my Story, and it will not let me tell other stories. I argue with my Story. I remind my Story that it belongs to me. It is too personal, too emotional, but even then my Story will not let me go. It sits staring at me, probing me with memories, interfering with my work. I protest, telling my Story that it leaves me vulnerable to criticism. I ask my Story to stop bothering me, to let me write something else, something publishable, something academic. “Besides,” I say, “people will misunderstand my Story.” “Tell me,” says the irritating Story. Reluctantly, I offer to start with Tillie Olsen’s working-class mother-narrator who is visited by an official (Olsen 1961).³ I begin with the Olsen’s use of ironing as a metaphor.

“I stand here ironing,” responds the mother when the official questions her, “and what you asked me moves tormented back and forth with the iron.” Here, ironing serves as a symbol of mothering: the repetition of daily chores; the steamy dilemma of questions for which there are no good answers; the pressing emotional toll of loving one’s children from the depth of one’s being. She is a woman who knows the hard labor of mothering.

The visiting official is an important man from an important office in the city. His brusque interrogation bears down upon her, “I wish you could manage the time to come in and talk with me about your daughter,” he says. “She’s a youngster who needs help and I’m deeply interested in helping.” Shamed by the official’s impervious manner and intrusive insistence, the mother pushes her iron into the clothes, red-faced, her back to him. She cannot face him. Later, pressed again by the official to answer a question about the help she needs, the mother sighs. She capitulates, accepting what he implies. She says, “[I am] engulfed with all I did or did not do, with what should have been and what cannot be helped.” Her words reveal her resignation, and I see it now, her sense of shame. Shame engulfs.

Ironing. Women’s work. Ironing is an iconic symbol of mothering, the 1950’s June Cleaver mothering, the pearl necklace, A-line gingham Hepcat dress, every-hair-in-place mothering. June Cleaver ironed but she looked beautiful doing it, and the image of her ironing reminds us that mothers are nurturers, they clothe and care for us, and if they are the June Cleaver good mother, they do it all with a smile without breaking a sweat. Ironing is a twenty-four-hour, seven-days-a-week job. And others are always telling you how to iron better, more effectively, and with a pleasant attitude. Or else.

“I hope this is enough,” I tell my Story. Do you see how I have to hide behind Olsen’s narrator? Even so, I am revealed in the way I describe her; in my old-fashioned choice of ironing as metaphor, my description of the official brusquely interrogating her, and in her shame. Notice, too, the mother’s choice of words—*tormented*, *engulfed*—so evocative, so visceral. So mothers. So me. I deeply feel her torment as though it is my own. I tell my Story that this sufficiently captures my Story.

“Go on,” says the persistent Story.

“When is there a time to sift, to weigh, to estimate, to total?” asks Olsen’s narrator as she stands ironing. Again, she uses the language of the good mother. Sifting flour, weighing children, totaling grocery bills. Her interrogator reminds her of how tired she is, how much there is to do and how little time left to do it. Dinner must

be made. Her daughter bathed and dressed for bed. A story read. A teacher's note answered. Then blessed sleep can come during which she hopes to feel nothing. This man asks her about the help she needs, but she knows he is not prepared to give her what she would ask for—someone other than herself to care deeply about her daughter's well-being and security, something other than herself to support her daughter's way in the world. Perhaps she does not deserve such things. Perhaps he is right, she needs his help. She tells him, "Because I have been dredging the past, and all that compounds a human being is so heavy and meaningful in me, I cannot endure it tonight." She wishes he would go away, but even if he leaves, the memories of the purpose of his visit and the useless authority that he represents bear down upon her and squeeze her heart. She has a flickering sensation that she caused her daughter's difficulties. If only she had been a better mother. Then she remembers the teacher who refused to help her daughter, the husband who left her alone with the children, the neighbor who complains about the noise, the unpaid bills, the forces beyond her control. Yet the quiver of self-blame remains ignited in her and her attempts to shift blame do not make her feel better. Shame persists.

Dredging the past? When did *I* have time to sift, to weigh, to total? I tell my Story that I must stop. Telling my Story will only cause problems for me. Someone will criticize me. People will see who I really am. My shame will be public.

"Continue," says the obnoxious Story.

At one point in ~~my~~ her story, Olsen's narrator echoes the lament of mothers throughout time, "I will start and there will be an interruption and I will have to gather it all again." The school will schedule an urgent meeting. The doctor will phone with test results. The babysitter will call in sick. The husband will want some attention. The neighbor will complain about "those Blacks" in wheelchairs living in the group home down the street before he sees my adult son, happy and Black and beautiful, hopping down the driveway. The ironing will have to be done. This is no June Cleaver life. This is real-life mothering tethered to the material world, ironing tormented back and forth, engulfed with all I did or did not do, with what should have been and what cannot be helped.

I tell my Story that I have to stop. Telling is too difficult. I need the obscurity and comfort of citations and references (preferably in APA style but I will settle for MLA or Chicago). At least let me take a break and write a different story.

Silence.

Perhaps I ask too much? Yet silence suggests assent. So I try to tell my Story in a different way by drawing upon what others say.

MATERNAL TEXTS

The maternal text is written in stereotypes of mothers integrated into the fabric of mothering. Numerous mother tropes can be found in the literature on mothering (Wamer 2005), and tropes come with a set of assumptions presenting numerous

opportunities for mother-shaming. Rich identifies the trope of the self-denying good mother who is long-suffering, patient, sane, free of complaint (Rich 1979; Seiter 1986), until she is not; the 1990's suburban, Clinton-era, soccer mom obsessed with driving her children to their sports events to prepare them for the harried, middle-class, adult life. Tiger mother's high expectations and parenting style are associated with preparing children to compete in a competitive world (Chua 2011). A smothering mother is blamed for raising a neurotic child (Harrington 2016). Amy Sousa writes about refrigerator mothers and warrior-hero mothers (Sousa 2011). Refrigerator mothers were once believed to create autism (Kanner 1949).

Mother is expected to do everything right, but when "mistakes" are made, as when she mothers a disabled child, her status as mother is diminished (Sousa 2011) as is her social position. Along with her child, this mother may sit outside the circle of belonging, looking in but seldom getting in. Officials can offer to help or intervene, but they cannot offer her what she or her child need. Can they give her more than twenty-four hours in a day? Will they require the neighborhood children to play with her child? Will someone assure her that her adult child will be a valued member of the local community when she is no longer able to support and defend him? ⁴ If she cannot be the good mother, she is no mother at all.

Ableism writes the maternal text for mothers of disabled children (Thomas 2003) by stealing the traditional and anticipated role of mother from a woman (Frantis 2013). For example, middle-class American mothers anticipate ball games, birthday parties, and significant coming-of-age rituals like the high-school senior prom or a wedding or the birth of a grandchild. Mothers of disabled children with significant support needs may not experience these coming-of-age rituals that serve as symbolic acts of shared values and beliefs (Coyne and Mathers 2011) forming the social glue marking who belongs and does not belong to a community. Even legal discourse is rife with mother tropes that portray mothers as outsiders, either pushy and aggressive or not pushy enough and not aggressive enough (Colker 2015). These are mothers in a double bind: they do too much or not enough, but they never do the right amount of anything.

That the diminished mother is no longer an example of the good mother is evident in the published narratives of the birth stories of mothers of children with Down syndrome who describe how medical providers teach them about the deviancy discourse of mothering a disabled child (Gabel and Kotel 2015).⁵ The narratives reveal a nurse who will not look at one mother, a physician who refuses to enter the room of another mother, the mothers' newborns are quickly removed from them and whisked off to be examined while the mothers are left alone knowing their maternal texts are disrupted by something significant but not knowing what the disruption could be. Finally, when they learn their infants have Down syndrome, each mother's narrative draws on the same trope of the mother of a child with Down syndrome; she is tired, haggard, dirty. She has messy hair, old clothes, and unmanicured nails.⁶ In the narratives, I see comparisons to Olsen's mother-narrator. She is not the *good* mother, the June Cleaver mother.

Here is the deviancy discourse of mothering disabled children: mothers are valued to the extent that their children are valued (Landsman 1998, 2009). These post-natal mothers may eventually be praised by relatives, friends, and teachers. They may be immortalized in the media as sacrificial mothers who give up everything for their children who have significant support needs (Davies 1992). The sacrificial mother is epitomized in Erma Bombeck's poem, "The Special Mother" (Bombeck 1983). In it, God matches babies with mothers and patron saints, realizing at one point that a "handicapped child" needs a mother who has the right amount of patience "or she will drown in a sea of self-pity and despair," divinely associating the "handicapped child" with self-pity and despair. With the right amount of patience, argues God, "once the shock and resentment wear off she'll handle it." The angel assisting God asks who the child's patron saint will be and God says, "A mirror will suffice."

The poem fails to consider this mother will live with the confusion and isolation of being told that there is a "special place in heaven" for mothers like her, even though she is secretly aware of her own anxieties, fears, and shortcomings. She may be christened the cherished perfection of good mothering, but she does not benefit from placement on a pedestal. The pedestal quarantines her, ironically placing her above other mothers while debasing her and her child. Underneath the stereotype of the sacrificial mother is a disgust of her child and people like her child; a disgust that openly and frequently says, "There but for the grace of God..." It can be difficult to insinuate oneself into the circle of belonging from high atop a podium of disgust. As is expected of her, the sacrificial mother on the pedestal does not complain, resist, or argue with authority. She is the docile body of bio-power (Deveaux 1994). She is exactly what the systems of power need her to be—a compliant, self-denying matriarch—but she will harbor a troublesome sense that she cannot quite articulate; that the honor bestowed upon her for her "sacrifice" camouflages the socially imposed shame of her and her child's contributions to the world.

SHAME I: CAPITULATION AND CONCESSION

I drag my shame outside for a walk because it needs a little air . . .
 O how shameful my shame is!
 —Levy 2009

Affect⁷ is integrated with structure and politics via powerful discourses that circulate through and regulate emotions (Young 1990; Harding and Prilbram 2002; Pedwell and Whitehead 2012; Bargetz 2015; Lieb 2017). In the example of the sacrificial mother, a nationally published poem is passed from mother to daughter, friend to friend, re/producing the tropes of the sacrificial mother and the pitifully dependent disabled child. Olsen's mother-narrator is engulfed with shame by the authority of the official bearing down upon her. Mother stereotypes compel mothers to follow a script and criticize mothers who do not follow the script. In this way shame becomes the locus of control, integrating affect and structure.

Thus, the sacrificial mother has no time or energy for resistance. Instead, she is expected to smile, gratefully accept compliments about her unflinching dedication to her “damaged” child, and confess, “Yes, my child is damaged goods.” Very often, mothers who give birth to infants with Down syndrome are expected to have misgivings, worries, and doubts insidiously dissociated from structural hierarchies that devalue disabled people and, by extension, their mothers. The individualization of affect serves structure because it draws attention to mothers via shame and away from architectural hierarchies reinforced by the normative discourses of gender and disability that govern the mothers’ labor, delivery, and child-rearing (Gabel and Kotel 2015).

Lying in their postpartum beds, the mothers in Gabel and Kotel’s study do not apprehend the power structures that cause them to turn inward to ponder the “tragedy” they have delivered to the world.⁸ Their postpartum needs are ignored while their infants are examined, poked, and prodded toward a diagnosis of Down syndrome. The infants’ shame is diagnosed in the tell-tale physical characteristics of Down syndrome—the slant of their eyes, the deep crease in the palm of their hands, their flattened faces. The mothers’ shame is evident in their swollen bellies, birth fluids, and tears. Symptomatic of shame, their bodies betray them. The mothers’ first lesson in ableism is a socially negotiated embodied experience.

The mothers’ birth experiences exemplify the embodiment of shame. They are women imagining the mothers they have become as a result of the birth of children with Down syndrome. They have violated the give-birth-to-a-perfect-baby principle to which they feel bound (Bartky 1990), and their shame leaves them existentially naked and out of place (Janz 2011). They are exposed as flawed women (Brown 2006; Nurka 2012) who cannot deliver a “normal” child. They are socially rejected (Leeming and Boyle 2013) by medical staff who avoid or ignore them and by the lack of congratulations and celebrations from family and friends. Shame is “wrenchingly painful” (Nurka 2012, 318) and in her pain, each mother dreams that her infant has died.⁹

The mother who feels shame becomes partner with her own domination by capitulating and accepting the mantle of shame.¹⁰ In mother’s weak moments, shame says, “give up, stop fighting, and join me,” and for a period of time, resignation feels like relief. If mother relents, she no longer tilts at windmills struggling to convince others there is nothing wrong with her and her children. Then teachers and friends can say she is no longer in denial because she appears to accept her own fate and that of her children. When mother gives in to shame, she thinks, “at least I can have some peace,” but she may not realize that shame is embodied. She cannot leave her body and, even worse, shame “hides under [her] skin like a cold sore” (Stass 2008). Nor can she avoid shame’s publicity. Levy writes, “I drag my shame outside for a walk,” and “at first I wonder why people are looking at us, but then I look down, and get it—my shame, after all, exudes a certain odor (Levy 2009, 135).” Shame is fetid. Shame imagines the glances of others as reiterating shame, and in response, shame urges mother to concede the unworthiness of herself and her children. Even if she tries to resist, mother may not realize that shame is cellular. It wordlessly demands

acknowledgment and capitulation, as when Levy writes, “suddenly I feel it twitching, as if it’s about to make a run for it—which makes me grab its hand” (135). Yes, shame persists. Even at home surrounded by her family, mother may not forget her shame. Shame is familiar and ever-present, “waiting in the corner and ready to comfort” (Stass 2008).

INTERLUDE

My own mother gave me Bombeck’s poem in 1983 when I was a young mother. Many years later I realize that those who venerate the sacrificial mother wrongly believe that she is the gold standard of mothering when, in reality, she merely does what needs to be done. Someone has to do it. She is nothing special. My attempts to use other women’s words only lead me to myself. I am ironing, tormented back and forth, feeling like Olsen’s mother-narrator when the official asks her what she needs. I do not need money, but someone recently gave my husband \$100 because of the things we do for our “needy children.” How awful! They are the bright spots in my life, the oldest one approaching middle age. Yet we never have enough money for them to do the things they want to do, and this grantor is a member of our community. So I am both thankful and offended and once again conflicted, knowing that bestowals of money or reverential titles can be wolves in sheep’s clothing, requiring me to feel embarrassed about my children.

Like Olsen’s mother-narrator, I do not tell this man what we really need because he cannot give us inclusion and peace, a social or economic buttress during crises, and a freely lived life for my children when I am dead or incapacitated. These gifts are beyond the reach of one person. My daughter’s recent question rings in my ears, “will someone force me to live in a group home when you are gone?” Unfortunately, I cannot bear to tell her that the answer is “maybe” and even though I am blameless in this, I feel ashamed of evading her question and ashamed that she will live in a world in which she may be forced to leave her home when I am gone. Like Olsen’s narrator mother, I need *someone* other than myself to care deeply about my adult children, *something* other than myself to support my adult children’s way in the world.

SHAME II: TRANSITION

There are so many roots to the tree of anger
that sometimes the branches shatter before they bear.
—Lorde 1973

The sacrificial mother is self-denying and unacquainted with her affective options. She does not realize she has a right to be angry, so she steeps—soggy, numb, luke-warm—in her shame. She may harbor feelings she labels as frustration,

disappointment, or discouragement, but she is unlikely to call her feelings anger since anger is unbecoming of her gender and of the good mother. Therefore, she attributes negative emotions to her own shortcomings and attempts to wrangle and manage them as imperfections, even while she admits to her flaws and the shame of them. Cramming her emotions into dark penetralia, she thinks her shame is her own “experience of the self by the self” (Sedgwick 1995, 136). She eventually chokes on shame’s bile. It rises, she gulps it down. It rises again. She gulps again and again. She cannot afford to taste the sewage of self-pity. Better to swallow it. Better to avoid talking about it. Unfortunately, mother does not realize how shame is imposed on her by poetry clipped from the newspaper and offered in awe; stolen glances and swift glances away; other mothers shushing their children when they stare at her child; the friend or family member who does not have the time to babysit, visit, or call; the teacher who urges her to do more or less but never acknowledges her doing the right amount; the “faithful” who pray for her child to be healed and pray for her to have patience.

With each indignity dispensed to her or her children, mother has a prick of anger, but she is unaware of the tree of anger even when it germinates, sprouts, and swells within her. She does not realize that her shame can generate anger and anger can serve her purposes. Moments of heart-pounding, white-hot anger “eat clefts into her living” (Lorde 1981, 9) and she defensively pushes her anger away while berating herself for her unexpected brazenness. She is consumed with the hidden labor of managing her emotions, yet without embracing anger, the branches of her tree of anger may shatter before they serve her. The sacrificial mother does not understand that her emotions are attached to the productive field of power relations (Alford 2000) calling for her to be docile and divided from herself (Deveaux 1994), alienated and ashamed.

Shame criticizes. While she irons, Olsen’s mother-narrator avoids blaming her daughter’s cruel teacher, her husband who left the family, or the lack of social-welfare support. She blames herself and is entangled with her shame. She does not perceive the anger pulling at her intestines, clawing her stomach, muffling her heart. The weight of her shame is in the heavy cast iron she recently heated on the stove. She accepts the shame of her daughter’s disablement and the responsibility for not doing enough to make things right. Her resignation and fear of anger is the hot pad she uses to avoid burning her hand. She regrets not smiling enough at her daughter, not paying enough attention, not this, not that, not something else. The regret of her shame is her movement tormented back and forth, engulfed with all she did or did not do. The June Cleaver mother fares no better. She may not realize the delicate balancing act of good mothering. In her lovely dress and frilly apron and with her perfectly manicured nails, the good mother irons and pretends that she has done everything right. After all, dinner is in the oven, her children are doing their homework, her husband sits watching TV after a hard day at the office. What could go wrong?

When things eventually go askew, as they inevitably will, mother’s self-talk concludes with shame and deflects anger’s promise of transformation (Blackmon 2015). “If you get angry people will avoid you. People don’t like to be around angry mothers,” Shame cautions. “Anger increases your cortisol levels and makes you fat,” warns

Shame. "You know you can't think straight when you're angry," blames Shame. "It's OK to feel a little angry now and then but don't dwell on it," consoles Shame. "Your mother was angry and you don't want to be like her, do you?" reminds Shame. "Look at the wrinkles on your forehead. Staying angry will make them permanent," admonishes Shame.

One day with defenses weakened, mother startles bleary-eyed, unable to gulp anything down. What once felt colorless and listless now roils with flaming sparks of awareness. She realizes she is balanced precariously on a pedestal at the edge of a cliff. Shame, her familiar, now seems useless and weak, but what else is there? Mother teeters on her sacrificial pedestal. She does not perceive the throbbing, drumming, vibrating in her chest as the pulse of anger. This is the gift of transformation but will she seize it? It feels dangerous and risky and she tries to push it away, hoping to bury the unfamiliar. She peers across the affective chasm, dangling helplessly on shame, sometimes with barely a toehold, other times on her knees and clutching the edge, white-knuckled and tearful. She is afraid to leave shame and vault toward anger. She is paralyzed by the dizzying rush for which she has no vocabulary, no intimacy. If she jumps, she may fall and be lost. If she stays where she is, she remains on familiar ground perilously close to habitus.

Mother can now see her options. If mother takes the risk and leaps toward anger, she may fall and have to climb back up. Having fallen, she is fully awake, heart pumping, breathing heavily. She can clamber back to her pedestal where life is mundane and anemic but oh so familiar. This is an easy climb. The footholds are where she remembers them. Her hands know where to grasp without looking. The pedestal may not be so bad after all, with its permanent impression of her heavy body. See the people on the edge of the cliff waving mother to climb up? Her daughter's teacher, her son's doctor, the neighbor next door, the family member, the restaurant owner/bus driver/store clerk/social worker, even Erma Bombeck, though she has been dead many years. Or mother can choose the more difficult ascent. She can scratch and claw her way toward anger, but mother, do not look up! Stay focused on securely placing hands and feet. Ignore the cacophony coming from behind, urging you to descend. If you reach the top, you become a new mother, a vigilante mother (DiQuinzio 1993; Blum 2007). You will insist that your children live dignified lives. You will resist policies that segregate your children "for their own good" or because "this is the best placement" or "this is where we have the resources and teachers who are trained to deal with your child." You will embrace your outsider status as a woman who "viscerally understands the world because [you have] the vantage point of outsiders looking in on it" (Locke 2007, 152). This will be an uncomfortable embrace—pariah, marginal, peripheral woman engorged with powerful, agitated, compelling fury. Cling to anger and despite ridicule, stigmatization, misunderstanding, and blame, you will refuse to accept that your children are less deserving and you will have the strength and courage to withstand.

Anger is the vigilante mother's response to injustice (Lorde 1973; 1981; Bell 2005; Taylor and Risman 2006; McWeeny 2010). Her anger bears witness to her own and her child's marginal social location, thus giving the vigilante mother the

authority (Narayan 1988) to speak about ableism from her unique perspective and as an ally to her children. In spite of her diminished status as a woman (Ruddick 1980; Keller 2010) and the mother of a disabled child, the vigilante mother labels her anger and uses its power as an agonistic site of resistance against structural inequity (Deveaux 1994; Pedwell and Whitehead 2012). She is grateful for her shame because it gives meaning to her mothering, reveals the world as it is rather than as she wants it to be or as she is told it must be, and propels her toward anger.

INTERLUDE

As I write I can almost feel anger's heart-pounding adrenaline rush. I sense remnants of my own unacknowledged and unwelcomed anger. "Why didn't anyone tell me I was angry?" I ask my Story. Though irritating earlier, my Story gently reminds me that Audre showed me that I am an angry mother (Lorde 1981).

I finally realize ~~who~~ what can soothe and comfort me. I embrace my anger and direct it outward toward the architecture of my children's suffering. My children have been examined and found less worthy of social acceptance, and I have suffered those wrongs with them and for them. We are like Joseph K. in Kafka's *The Trial* (Kafka 1995),¹¹ prosecuted for charges that have not, and will not, be explained. K's story begins with the narrator saying, "Someone must have been telling lies about Joseph K., he knew he had done nothing wrong but, one morning, he was arrested." It is K's thirtieth birthday and he is sleeping in his bedclothes. Confused, K tries to leave his room, but an officer tells him to stay put "for [his] own good." Next there are two officers.

They seem to appear without forewarning. K asks for the officers' identification papers and arrest warrant and they say, "In a position like yours and you think you can start giving orders, do you? It won't do you any good to get us on the wrong side, even if you think it will—we're probably more on your side than anyone else you know!"

Patronizingly, the officers admit that they are there to find out what kind of person K is before the arrest warrant is issued. K is confused. He does not know the law that allows them to do this and asks them to explain. One of the officers says to the others, "Look at this... he admits he doesn't know the law and at the same time insists that he's innocent." K's whole world is turned upside down and nothing makes sense to him anymore.

Next a supervisor is present, surprising K by suggesting that K should go to his job at the bank. Confused, K wonders how he can go to work if he is under arrest. The supervisor seems to think nothing of this, saying, "It's true that you're under arrest, but that shouldn't stop you from carrying out your job. And there shouldn't be anything to stop you carrying on with your usual life." K dryly responds, "It hardly seems to have been necessary to notify me of the arrest in that case."

What is a "usual life" under arrest? Before you know you are under arrest, it can seem like a usual life, but once you realize you are under arrest, everything changes.

You finally grasp you are living in a carnival fun house where the floors tilt and move to catch you off balance and where the mirrors distort what you expect to see. Every cautious step is a reminder of why your reflection is distorted. You see yourself the way others see you, a bloated, asymmetrical caricature of the good mother. Yes, how does one live a normal life while under arrest?

One day, K receives a phone call telling him he has a hearing about his case the following Sunday. He learns “that these cross examinations would follow one another regularly, perhaps not every week but quite frequently.” K wonders how often he might be cross examined. When K finally gets his day in court, he pleads with the judge: “What has happened to me is not just an isolated case. If it were it would not be of much importance as it’s not of much importance to me, but it is a symptom of proceedings which are carried out against many.” Perhaps K doesn’t know that cross examinations can take many forms. K is not the only individual whose bedroom has been violated, whose guilt has been predetermined, whose usual life has been interrupted. He is not the only one who is told to return to work and act as though nothing bizarre has happened. He is not the only one who is told that the arresting officers are on his side.

Later, imploring the judge, K says, “All I want is a public discussion of a public wrong.” After all, the story is not about K, nor is it about K’s innocence or guilt. It is not about this one individual—K—or one mother or any one person. Instead, it is about what requires shame from K, or mothers, or disabled children, or disabled people. In his supplication, K reveals the truth about mothering disabled children. “All I want is a public discussion of a public wrong,” says K, whose request is met with jeers from the courtroom audience, many of whom also have been arrested like this. K’s is not the first arrest, nor will it be the last. K reaches the point where he reacts against the architecture of oppression by implicating the state in a public wrong. Perhaps he is angry. Perhaps his reaction is gendered in that he feels entitled to an explanation and a public discussion. Yet there is no public discussion of the public wrong, and the case ends as it began—as a question of K’s guilt and K’s alone. K’s shame morphs into indignation and anger. Near the end of his story, K is despondent and says, “It was as if the shame of it was to outlive him.” The shame is not his to bear.

POSTLUDE

“Forged in the crucible of difference,” many mothers of disabled children stand outside the “circle of acceptable women” (Lorde 1984, 112). They bear the weight of the oppression of their children and the social pressure to be the good or sacrificial mother. They “suffer in body and soul with and for [their] children” (Rich 1979, 278). Firmly planted on a pedestal, sacrificial mothers may unconsciously take their shame outside for a walk in ableism’s full view. In contrast, vigilante mothers no longer find shame attractive. Instead, they know that the gilded pedestal is an alibi for ableism and shame is not theirs to bear.

NOTES

I gratefully acknowledge Clara Fischer for her editorial insight and persistence, four anonymous reviewers for their critical acumen, and my colleague Jasmine Ulmer for her thoughtful reading and feedback.

1. Tanya Titchkosky explains this usage, “disabled children,” which is similar to the term *minoritized*, as in “minoritized children” (Titchkosky 2001).

2. I could ask my children for permission to use their stories. But ethically, my children are considered vulnerable participants, and any use of their words, experiences, or perspectives should involve my permission. I could appropriate my children’s stories without their permission (other academics have done so), but I will not do it. Any reference to my children is my perspective as their mother. I do not speak for my children.

3. Olsen’s short story, “I Stand Here Ironing,” is found in her book of short stories, *Tell Me a Riddle* (Olsen 1961). This story won the O’Henry Award for the best short story of 1961. In it, a mother irons while reflecting on her years of raising her daughter, who is represented as a girl who had difficulty in school.

4. I ask myself these questions.

5. The social interpretation of disability does not refer to specific disability categories since they are associated with the medical model of disability (Garland-Thomson 2005). Instead, the social model focuses on oppressive structures. Birth stories of mothers of children with Down syndrome are an obvious example of embodied mothering within deviance discourses of disability.

6. This paragraph reflects what the mothers told Susan Gabel and Kathy Kotel (Gabel and Kotel 2015).

7. Elspeth Probyn observes that affect is physiological and biological whereas emotion is a cultural or social expression (Probyn 2005). Brigitte Bargetz proposes that affect, feeling, and emotion “emphasize the bodily, psychic, and cognitive dimensions of affect” (Bargetz 2015, 582). I use affect to connote its biophysicality (for example, Probyn 2005), which I view as integrated with social expression.

8. This paragraph and the next are my use of the mothers’ words to theorize shame.

9. Every mother is quoted in Gabel and Kotel 2015 as saying she dreamed of her infant dying.

10. Gabel and Kotel (2015) do not theorize shame but the narratives they report provide material for theorizing shame in this section.

11. Published in 1925, *The Trial* is a story of a man arrested and prosecuted for an unknown crime. Its theme of state power used against individuals is one of Kafka’s common motifs.

REFERENCES

- Alford, C. Fred. 2000. Sex, power, and the politics of identity. In *Foucault live: Collected interviews*, ed. Sylvere Lotringer. New York: Semiotext(e).
- Bargetz, Brigitte. 2015. The distribution of emotions: Affective politics of emancipation. *Hypatia* 30 (3): 580–96.

- Bartky, Sandra Lee. 1990. *Femininity and domination*. New York: Routledge.
- Bell, McAlister. 2005. A woman's scorn: Toward a feminist defense of contempt as a moral emotion. *Hypatia* 20 (4): 80–93.
- Blackmon, Lisa. 2015. Affective politics, debility and hearing voices: Towards a feminist politics of ordinary suffering. *Feminist Review* 111: 25–41.
- Blum, Linda M. 2007. Mother-blame in the Prozac nation: Raising kids with invisible disabilities. *Gender and Society* 21 (2): 202–26.
- Bombeck, Erma. 1983. *Motherhood: The second oldest profession*. New York: Open Road Integrated Media.
- Brooks, Thom. 2008. Shame on you, shame on me? Nussbaum on shame punishment. *Journal of Applied Philosophy* 25 (4): 322–34.
- Brown, Brené. 2006. Shame resilience theory: A grounded theory study on women and shame. *Families in Society* 87 (1): 43–52.
- Chua, Amy. 2011. *Battle hymn of the tiger mother*. London: Bloomsbury.
- Colker, Ruth. 2015. Blaming mothers: A disability perspective. *Boston University Law Review* 95 (3): 1205–24.
- Coyne, Christopher J., and Rachel L. Mathers. 2011. Rituals: An economic interpretation. *Journal of Economic Behavior and Organization* 78 (1–2): 74–84.
- Davies, Bronwyn. 1992. Women's subjectivity and feminist stories. In *Investigating subjectivity: Research on lived experience*, ed. Carolyn Ellis and Michael Flaherty. Newbury Park, Calif.: Sage.
- Deveaux, Monique. 1994. Feminism and empowerment: A critical reading of Foucault. *Feminist Studies* 20 (2): 223–47.
- DiQuinzio, Patrice. 1993. Exclusion and essentialism in feminist theory: The problem of mothering. *Hypatia* 8 (3): 1–20.
- Finkelstein, Vic. 2001. The social model of disability repossessed. <http://disability-studies.leeds.ac.uk/files/library/finkelstein-soc-mod-repossessed.pdf> (accessed January 26, 2017).
- Foucault, Michel. 1977. *Discipline and punish*. New York: Pantheon Books.
- . 1982. The subject and power. *Critical Inquiry* 8 (4): 777–95.
- . 1991. Preface to *The history of sexuality*, vol. II. In *The Foucault Reader*, ed. P. Rabinow. Harmondsworth, UK: Penguin.
- Frantis, Linnea. 2013. Mothers as storytellers. In *Disability and mothering: Liminal spaces of embodied knowledge*, ed. Cynthia-Wilson and Jen Cellio. Syracuse, NY: Syracuse University Press.
- Gabel, Susan L., and Kathy Kotel. 2015. Motherhood in the context of normative discourse: Birth stories of mothers of children with Down syndrome. *Journal of Medical Humanities* 1–15. <https://doi.org/10.1007/s10912-015-9367-z> (accessed December 4, 2017).
- Galligan, Phillip. 2014. Shame, publicity, and self-esteem. *Ratio* 29 (1): 57–72.
- Garland-Thomson, Rosemarie. 2005. Feminist disability studies. *Signs* 30 (2): 1557–87.
- Gilbert, Paul. 2003. Evolution, social roles, and the differences in shame and guilt. *Social Research* 70 (4): 1205–30.
- Harding, Jennifer, and Deidre E. Prilbram. 2002. The power of feeling: Locating emotions in culture. *European Journal of Cultural Studies* 5 (4): 407–26.

- Harrington, Anne. 2016. Mother love and mental illness: An emotional history. *Osiris* 31 (1): 94–115.
- Janz, Bruce B. 2011. Shame and silence. *South African Journal of Philosophy* 3 (4): 462–71.
- Kafka, Franz. 1925/1995. *The trial*. Trans. George Steiner, Willa Muir, and Edwin Muir. New York: Schocken Books.
- Kanner, Leo. 1949. Problems of nosology and psychodynamics of early infantile autism. *American Journal of Orthopsychiatry, Mental Health, and Social Justice* 19 (3): 416–26.
- Keller, Jean. 2010. Rethinking Ruddick and the ethnocentrism critique of *Maternal thinking*. *Hypatia* 25 (4): 834–51.
- Kittay, Eva Feder. 1999. *Love's labor: Essays on women, equality, and dependency*. New York: Routledge.
- Landsman, Gail. 1998. Reconstructing motherhood in the age of “perfect” babies: Mothers of infants and toddlers with disabilities. *Signs* 24 (1): 69–99.
- . 2009. *Reconstructing motherhood and disability in the age of “perfect” babies*. New York: Routledge.
- Lavlani, Priya. 2011. Constructing the (m)other: Dominant and contested narratives on mothering a child with Down Syndrome. *Narrative Inquiry* 21 (2): 276–93.
- Leeming, Dawn, and Mary Boyle. 2013. Managing shame: An interpersonal perspective. *British Journal of Social Psychology* 52 (1): 140–60.
- Levy, Rich. 2009. Shame. *Callaloo* 32 (1): 135–36.
- Lieb, Robert S. 2017. Spaces of the self: Foucault and Goffman on the micro-physics of discipline. *Philosophy Today* 61 (1): 139–210.
- Locke, Jill. 2007. Shame and the future of feminism. *Hypatia* 22 (4): 146–62.
- Lorde, Audre. 1973. Who said it was simple. In *From a land where other people live*. Detroit: Broadside Press.
- . 1981. The uses of anger. *Women's Studies Quarterly* 9 (3): 7–10.
- . 1984. *Sister outsider*. Berkeley: Crossing Press.
- Lyerly, Anne Drapkin. 2006. Shame, gender, birth. *Hypatia* 21 (1): 101–18.
- McWeeny, Jen. 2010. Liberating anger, embodying knowledge: A comparative study of María Lugones and Zen Master Hakuin. *Hypatia* 25 (2): 295–315.
- Narayan, Uma. 1988. Working together across difference: Some considerations on emotions and political practice. *Hypatia* 3 (2): 31–47.
- Nurka, Camille. 2012. Feminine shame/masculine disgrace: A literary excursion through gender and embodied emotion. *Cultural Studies Review* 18 (3): 311–33.
- Nussbaum, Martha C. 2006. *Hiding from humanity: Disgust, shame, and the law*. Princeton: Princeton University Press.
- Olsen, Tillie. 1961. *Tell me a riddle*. New York: Dell.
- Pedwell, Carolyn, and Anne Whitehead. 2012. Affecting feminism: Questions of feeling in feminist theory. *Feminist Theory* 13 (2): 115–29.
- Probyn, Elspeth. 2005. *Blush: Faces of shame*. Minneapolis: University of Minnesota Press.
- Rich, Adrienne. 1979. *Of woman born: Motherhood as experience and institution*. New York: Norton.
- Ruddick, Sara. 1980. Maternal thinking. *Feminist Studies* 6 (2): 342–67.

- Sedgwick, Eve Kosofsky. 1995. Shame-humiliation and contempt-disgust. In *Shame and its sisters: A Silvan Tomkins reader*, ed. E. K. Sedgwick and A. Frank. Durham, N.C.: Duke University Press.
- . 2003. *Touching feeling: Affect, pedagogy, performativity*. Durham, N.C.: Duke University Press.
- Seiter, Ellen. 1986. Feminism and ideology: The “terms” of women’s stereotypes. *Feminist Review* 22 (Spring): 58–81.
- Sousa, Amy C. 2011. From refrigerator mothers to warrior-heroines: The cultural identity transformation of mothers raising children with intellectual disabilities. *Symbolic Interaction* 34 (2): 220–43.
- Stass, Beth. 2008. Shame. *North American Review* 293 (5): 38.
- Taylor, Tiffany, and Barbara J. Risman. 2006. Doing difference or speaking up: Deconstructing the experience and expression of anger. *Race, Gender and Class* 13 (3–4): 60–80.
- Thomas, Trudelle. 2003. Misfit mothers: Memoir by mothers of children with disabilities. *Journal of the Association for Research on Mothering* 5 (1): 186–97.
- Titchkosky, Tanya. 2001. Disability: A rose by any other name? “People-first” language in Canadian society. *Canadian Review of Sociology and Anthropology* 38 (2): 125–40.
- Warner, Judith. 2005. *Perfect madness: Motherhood in the age of anxiety*. New York: Riverhead Books.
- Young, Iris Marion. 1990. *Justice and the politics of difference*. Princeton: Princeton University Press.