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Stigma, Belonging and Mothering

An Outsider's Understanding of Disability

Sitting in an overheated nook behind a bustling nurses' station we learned our infant daughter had permanent brain damage. What followed was a queer family's struggle with medical providers, a shift from success to survival, and a near divorce with feminism. But this is not merely the tragedy of a family mourning a loss, rather it is the real effort of two mothers to understand ability and disability from the uncomfortable location of outsiders as well as advocates.

I began this paper wondering where I should start. Do I start by asking if you know how socially unacceptable it is to insist to hoards of doctors that your child is not normal? Do I start by trying to describe how it feels when a paradigm shifts? Do I start with definitions of “feminist theory,” “disability studies,” “embodiment,” “narrative,” “socialization” and “deconstruction” and maybe even cerebral palsy for those who picture children from the 1950s trapped in wheel chairs and locked away in institutions? Do I follow a historical timeline of a happy family forever changed but promise a happy ending to keep you reading? Do I include words like “pain,” “grief,” “mourning,” “anger,” words that created a chasm between myself and my feminist community? Do I begin with a photo of my daughter that leaves you so stunned by her luscious curls that you are unable to pay attention to anything else I say, or do I begin with a photo of that same girl encased in leg braces tangled in her own muscles crying on our hard wooden floor? Do I invoke pity, shame, or god forbid bitterness or even some joy? It is a tricky decision to make, to straddle theory and personal history. To delve into a narrative of mothering takes real courage.

When I think of writing narratives on mothering I feel like I diminish the agency of my own flesh and blood, as though I write the body narratives of

each of my children without giving them the opportunity to author their own. I think of Daphne Patai and the only place her criticism stings when she says people “who stay up nights worrying about representation” are “privileged academics engaged in the erotics of their own language game,” and wonder if I can conjure self-reflexivity and lived truth without engaging in a tiresome academic fad known as subjectivity (69).

So I decide I'll start here, with the story of a lesbian couple from the Midwest. The story of a picket fence kind of life, where when I laid on an examination table and was told by an ultrasound technician that we were having twins one crisp November day we cried happy tears. And when our then two-year-old began chirping “two babies, two babies” we just laughed and made plans to buy a minivan. Nine months later August and Greta, our fairytale twins were born. August fair as snow and skin like a sugar cookie and Greta dark, curly, and made of gingerbread. Our OBGYN hugged me triumphantly after their delivery, a 30-minute ordeal with over 20 people present, where Greta had to be manually turned from breach to vertex and where I lost so much blood it makes my partner weak in her knees to look back at photographs of the event.

Eighteen months later, August, or Gus as we had taken to calling him, and Greta were six months old and my partner and I began to talk, shouting conversations from distant rooms, text messaging between classes, emailing, never looking at each other, never eye to eye. The twins had a way of making both a real physical divide between us by just their very presence and their constant unrelenting demands as well as a psychic chasm caused by lack of sleep and deep exhaustion.

“Greta can't pass a toy from hand to hand,” I text from under the table on my cell phone during a meeting where I should have been contributing to bylaw revisions.

“She won't even use her left hand!” my partner writes back hours later after I presume she tried to hand Greta nearly anything within reach to inspire her to use her left hand.

“Greta's tongue is always poking out of her lips!” she shouts from the kitchen when she successfully feeds Gus an entire jar of peas while Greta merely pushes the food from her mouth and lets it slide down her chin.

“Greta can't roll over” in an email, “She doesn't even try, in fact she still gets startled like a newborn when I lie her down” my partner writes as winter approaches.

“Greta failed her hearing test again!” over text message before I sit down to class, this after getting tubes put in her ears which we were told would fix her mysterious hearing problems.

In the bitter cold of a Missouri winter night we stood on our front porch alone as the kids slept. Eye to eye, smoking a cigarette for the first time since

we quit nearly seven years ago, we both said out loud to each other, “something is wrong with Greta.”

A few weeks later and a seizure fortuitously caught on video, we find ourselves with Greta admitted to the hospital and face to face with a daunting medical team who varied from dangerously incompetent to shockingly kind. We were taken to a computer screen behind a nurses’ station by the neurologist on call. Black patches on the MRI of Greta’s brain were clear as day, I saw them before the doctor even said a thing. This, I knew, was permanent brain damage. I still remember the faux leather fabric of the chair I gripped to keep from falling down and the searing temperature of the room. The neurologist was thrilled, “old stroke” he said “probably happened right before, during or after birth, this won’t happen again.” He thrust some handouts on the type of epilepsy she had, benign myclonic infant epilepsy, into our hands and sent us home the next day.

I wrote months later in a piece of creative non-fiction published in *Paradigm’s* most recent issue from September of 2010 that since then we’ve “been spectators of a disaster. Picking up shards of a family. Tucking photos into dusty shoeboxes instead of scrapbooks. Pointing fingers and fighting wars over our kitchen counter.”

But what I couldn’t write in that piece was that a postmodern rewrite of the truth occurred that day. That I have since been struck by visions of the surf rising up to steal the flimsy walls of the sand castles left on the shore, erasing my home. That reality is fragile. I traveled back in time to before the twins were born to re-experience those last ghastly days of elephantine size and that “triumphant” delivery to rewrite that time as the last time things were technically okay.

Elaine Scarry, feminist philosopher wrote in her 1985 seminal work on pain that, “pain is radically private” (4). Scarry is right. Pain is not only private and subjective, it also creates a divide between the sufferer and the observer. I cried embarrassing tears in a family restaurant we visited after the follow-up with the pediatrician where she used the words “cerebral palsy” and “Greta” in the same sentence. She tried to make me feel better, saying “sometimes things like this just happen and we never know when or why.”

I said to my partner nearly hysterical “this moment when Greta’s life changed forever could have been at any time, I could have been tying our son’s shoe, writing an email, taking a shower. This moment just passed us by.” I wanted a monument erected.

My partner and I turned our backs on each other and fell into our respective feminist training. We went into activist mode trying to get every possible service and therapist lined up to “fix” this problem. I cleaned our home and made kindly small talk with each specialist firing one after another until we

found a team that we could actually stand. I cheerily sang “Greta’s walking song,” a ditty intended to help her focus during therapy with inane lyrics sung to the tune of Frère Jacques. I chose the color of her leg braces in cheerful purple and green and dryly told the orthotics specialist when she suggested I choose something that would better blend with her skin that “the jig was up.” I rubbed and gently stretched the tight muscles of her left side, prying open her fist. But inside I bore a pain, unlike any other, and as Scarry suggested, I bore it alone.

The mothers of other disabled children in my community saw their children as blessings, said they had “special powers” not special needs. They said they were gifts from god and angels sent to teach them about life. I crumpled up the flyer of an infant stroke support group after imagining a group of Mid-western housewives complaining about how to get their husbands to do more housework.

I was at the National Women’s Studies Association conference a few years ago in Chicago. I was reading a piece of non-fiction during the creative writer’s session. It was an unremarkable trip, except that what I always remember is the woman who presented before me. She was a performance artist and laid out a white scrap of linen on the floor and upon it drew a conjuring circle as she spoke. She talked about fairies, about how they stir up trouble and are misunderstood. She wasn’t a mother, she was debating having kids at all, and she worried she was tempting the troublesome representatives of the nether world to punish her for her maternal desire. She told us how they played tricks and stole babies and substituted changelings. Her performance felt like a warning, like a message I ignored, I wondered if I was being punished for the selfishness of asking the universe for more.

Would it help if I told you that I never expected things to be perfect? That I knew supermom wasn’t even possible for me given that we are lesbian parents, that I love McDonalds and that we live on the edge of poverty? That even though we laughed like hyenas and were so stunned we couldn’t find our car in the parking lot after being shown those two tiny beating hearts back in that ultrasound room on that November day, that we still doubted how on earth we could raise these babies. That we had mighty fights over crib placement, car seat installation, and chore division, just like everyone else?

You see, before learning about Greta’s stroke, feminism was the answer to all my pre-born daughter’s problems. But suddenly places where disability and feminism intersected didn’t really feel like home to me anymore. After all, one of the most basic tenants of feminism is personal autonomy and what if that wasn’t possible for Greta? And while the cause and timing of her stroke remain unknown, what if it had been visible in that first ultrasound, where would reproductive rights leave me, with a choice to make? That didn’t really feel like

empowerment, not when you're looking back on a decision almost impossible to make. And choice is funny to think about since we obviously chose to have these children. A day doesn't go by when a stranger doesn't ask me if I used fertility medication to have twins (I didn't, for the record). But even if I had: two women and two babies, we made our own bed we should have to lie in it, even if that bed had the rumbled covers and uneven mattress of disability.

And this is where in this winding story I got temporarily kicked out of feminism. Both my physical and online feminist communities gave me the boot. It was too self indulgent to talk about these things. A blog we created, "Walking with Greta"—mostly to update family of Greta's progress and to dodge long phone calls—quickly became an outlet for our current state of mind. I was told it was cruel to my child who might stumble upon it later in life. One day I wrote a post titled, "Good Grief."

What is "good" grief? Is it progressing quickly through Elizabeth Kübler-Ross's five stages (denial, anger, bargaining, depression, acceptance) in a timely manner culminating in the development of a neat inspirational saying meant to carry you through the rest of your life? "She'll make her way," "god doesn't give you more than you can handle," "what doesn't kill you makes you stronger." Well, you get the idea. Is it coming through something painful with deeper insight into the meaning of life as many books devoted to the subject suggest? I really can't be sure but I know there is a strongly held belief out there that grief can be good.

I thought the "good" grief was the kind you felt fleetingly. The sad song that made you think of a time in your childhood, the tossing of your son's too-small shoes he wore as a baby into the giveaway pile, reminiscing with an old friend about your crazy teenage years. All those times we realize we can never go back, that sometimes things are gone forever. To me the "good" was the mourning for time past while knowing you were okay with moving forward into the future.

Greta, I do not have "good" grief. I am not flying through Kübler-Ross's stages of grief nor adopting some motivational saying to assuage my broken heart. I am reading the disability statement on my class syllabus over and over thinking of you. I am fighting the urge to turn over my table Real Housewives style when I hear a fellow student assert with all the stupid confidence of an unmarred life that "you make your own luck." I'm sneaking up on our memory box and creaking open the lid to shove your first pair of leg braces in the crack lest I catch a glimpse of the hat you wore when you came home from the nursery. I am eating handfuls of Tums to make the pain in my chest stop. I'm developing a theory about how best to deal with errant fallen tears (don't wipe just dab). I'm throwing away my lunch because accidentally stumbling upon your birth announcement in my sent box made me wonder if I could

ever be that happy again and made my food taste like sawdust. I'm putting on a fake smile everyday from behind my desk, from our kitchen table, and from our living room floor.

But Greta you are not the biggest tragedy of my life. I do not grieve for your existence or wish you away. I would not enter my fictional time machine with the purpose of erasing you. I would change so many things but never would I change you. Between you and me, those "good" grief peddlers are liars, and I expect you too to have days when everything feels impossible. But I also expect us both to have those days when it feels like anything is possible too. I can't offer you a cure to the bad days but I can offer you honesty.

So here's to all you grieverers out there. You will find no inspirational quotes here or promises that time will heal your wounds, just the hope that you get to feel the "good" grief instead of this.

We had to shut down the blog temporarily after it went up, and it was feedback of my online feminist mothering group that picked our bones and called us villains. That claimed we acted as though she ruined our lives. But there is a clear disconnect between my reality and theirs. I felt that it was possible to feel great sadness for the difficulties your child faces because of their physical limitations and still feel great joy at their existence. But mothering and children are precious and must be protected against any ugliness. The most popular contemporary literature on the subject of parenting a disabled child tells parents to think of having a child with a disability as planning a trip to Paris and suddenly finding yourself in Holland instead. It would take awhile to deal with the shock of being somewhere unplanned, but soon you would realize how wonderful your new destination was and start seeing the wonders of Holland and forget all about Paris. I pictured Greta in a field of blazing red tulips with windmills whirring in the background, unable to get up off the ground to pluck the petals of the flowers or feel the breeze from the mountains. Holland, Paris, both seemed ridiculous. But mourning that loss for her was not socially acceptable.

I read Jane Bernstein's book, *Loving Rachel*, where she takes her audience on a journey through her daughter's diagnosis of mental retardation and vision impairment and her ultimate acceptance and optimism at her child's future. Then I read the follow-up *Rachel in the World* where Bernstein was now divorced, stuck with a violent and maddeningly difficult child who needed constant care that not only wasn't affordable but didn't really exist. Here was a mother who had left Holland behind and landed somewhere less fun, like reality. Slowly I found other books, articles, blogs that allowed for the truth about raising disabled children without insisting on a veil of faith and hope. I began to think more about disability and feminism as existing together.

Disability Studies insists that this constant obsession with normal is offensive. That trying to mold Greta into a normal other was allowing society to write her body narrative instead of herself. Nowhere was this obsession with normal more evident than in the medical world. Every doctor, even those exhilaratingly innovative, needed us to know that we could make her talk normal, that her leg braces would make her walk normal, that her hand splint would make her appear normal. I wanted to challenge the idea of normal in those cold examine rooms but felt I would be putting Greta in harms way. Plus I know that normal isn't really even enough sometimes. I often thought, Greta may have a limp but she will have to be perfect in every other way to make it in this world. It was a very un-feminist thought, it doesn't challenge the status quo or call for activism at all. It is timid and selfish. It was official; feminism and I were now suffering irreconcilable differences on both sides of the fence. Friends and colleagues stopped calling for play dates. Strangers looked at Greta like she was contagious.

One night when my oldest son couldn't sleep he asked me why Greta didn't use her hand right, why she couldn't walk. I told him she got hurt when she was just a little baby in my tummy. I tried not to cry when I told him this, but still did. He patted me, "It's okay, mommy," he said. And he was right. He is right.

I hinted at a happy ending so here it is. Greta is doing great. She is the rock star of the cerebral palsy clinic, clinking and clattering in her Frankenstein walk she learned a full year earlier than expected. From a distance we look like a pretty normal family. Three kids jammed into a red wagon, two moms true, one little girl slumped to the side unable to hang on, but happy nonetheless. Our family calendar is bursting with appointments for physical therapy, occupational therapy, speech therapy, but we've found a way to accommodate all Greta's needs and still find time for fun. While I wish we could have suddenly understood our outsider disability status and what that meant as Greta's parents with a startling clap of clarity, I know these things take time. Slowly we found our way back to feminism, though bearing the scars of past wounds, we found ways to carve out space for feminism and disability that include scary words like "grief" and "sadness" but still contain "contentment" and "joy."

We hold on to each other and know in the extra moment we take staring at the trees letting Greta touch each leaf we may privately be mourning a loss, but that the day will still go on, and that we will still get back into the car and stop for ice cream on the way home just like any other family. We have grown accustomed to these halting moments where ability and disability collide and remind us of who we were, and who we are now, and allow room for both.

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