

Parenthood: Choices, Vices and Arts Expressions in Being a Disabled Parent

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Fran Flaherty and Ruth Fabby, disabled artist-mothers that have endured scrutiny, intrusion, judgement and criticism in adding to the population. Willing and equal to the task of motherhood, Fran and Ruth's stories of motherhood are full of unencouraging reprove. As artists, however, they suddenly realised, they've not made art about this. This paper will discuss the lack of representation of Deaf/disabled parents and its intersection with being a disabled artist. What happens to the narrative of disabled artist mothers in areas such as our reproductive rights, our freedom to choose birthing procedures? How can children of disabled artist-parents be supported? Why disabled artist-mothers do not readily represent these issues in their art? How important is it for disabled mother-artists to make art about being a disabled parent? What can institutions, arts and cultural producers do to support disabled parent-artists careers?

Introduction:

Anthropology of Motherhood: Culture of Care (AOM) is an ongoing social practice artwork and living archive started in 2015 by artist Fran Flaherty. Anthropology of Motherhood elevates the act of caregiving through fine art by transforming mundane objects of caregiving into valuable art pieces such as paintings, sculpture, and mixed media pieces. AOM explores and amplifies Disability Arts and the aesthetics of caregiving as an artistic practice centering design practices and social engagement. AOM, features works of art that engage in the complex visual, material, emotional, corporeal, and lived experiences of motherhood, caregiving, parenting, nurturing and maternal labor with the mission that societies should lead through gestures of care as a necessary grounding and reorientation.

The mission of the Anthropology of Motherhood is not just to elevate the culture of care into fine art but it's also to amplify disability aesthetics in art. This is reflective of the artwork that is curated into AoM's exhibits as well as the programming conducted in conjunction with this exhibit. In November of 2020, an event entitled "Disability Arts: An Empowerment Tool" was conducted by Ruth Fabby, Director of Disability Art Cmuryu (Wales). While preparing for this workshop Ruth was surprised by the gross lack of representation of artist-mothers/caregivers with disabilities that make work about their

caregiver roles. This paper will attempt to identify the reasons for that lack of representation and put forth a call to action to leaders and institutions to support visual artists, musicians, performers who are also caregivers to make work about their experience as disabled caregivers.

Personal Stories

My life has been a roller coaster of experiences, some good, many bad. My identity has been reflected through various prisms, from child, daughter, wife/partner, mother, artist/performer, but the one constant has been my identity as a deaf girl [I've been wearing aids since I was six] then a deaf woman and how this has affected every aspect of who I am.

I wanted to explore why I, as a Deaf/disabled parent, don't place my experiences of motherhood into my arts work. I feel that it is because we are persistently negated, disavowed as mothers and primary carers. We have to fight right from the onset, starting with the notions of being sexually active, being seen as fertile, in maintaining our pregnancies – if we so choose - keeping our children and having to prove to the various social systems around us, that we can manage.

In the UK, the NHS is to my mind what makes Britain great – but it is fraught with eugenics underpinnings in the training of its medical staff. At the age of 22, I was told that I would be irresponsible to continue with the pregnancy, as my child would be born deaf. At the age of 39 with my last pregnancy, I was portrayed as an eccentric as I didn't want to have the medical tests to see if my child carried any 'defects'. All this treatment makes you feel unduly on edge, ultra-protective and scared that your rights to be a mother could end at any moment.

I came into the arts late: it was after my first child was born. My education and family life were fraught with pain and rejection. Having a child gave me a purpose for the first time in my life, it also ignited my activism due to the Obstetricians' negative comments about the possibility of having a deaf child. Through my pregnancy, I became more in tune with my body: I explored natural childbirth reading the work of Leboyer 'Birth without Violence' and similar research. Yet, I had to fight the NHS to get the birth I wanted, things like no drugs, no cuts, no shaves and no clamping of the cord until the baby was breathing independently. I was scorned upon, constantly told 'you will get what you're given'! I started to experience how the system didn't like individuals, free-thinkers and especially a deafened woman wanting to take charge of her own body.

One of my hardest experiences was with my last child and how the school treated her with her diagnosis of Autism and ADHD. The teachers would not heed her triggers. Her

first year in senior school – in the UK aged 11/12 [year 7], the school insisted that the year group had to go away for a two-night outdoor adventure ‘bonding trip’. This meant sharing with the school about her food requirements, her sleeping patterns, her fear of water, her sensory overload and anxiety levels. She wrote a plan herself and she and I were assured this would all be taken into account. When the school bus arrived back – my child was physically handled and brought over to me with two teachers shouting as to how awful she was: that she had refused to get in a canoe, that she had not eaten their food, that she wouldn’t sleep and that she had actually run away. They relayed all this as she was standing there alongside me, head buried into my side, her tears ignored, and the blame totally shifted onto me: a bad parent.

In writing this I realised my artistic life has been unconsciously separated from the fight to help my children survive and thrive, to assure them they are beautiful, brilliant, unique. To ensure that they are not purely measured by the medical systems milestone indicators, the education systems curriculum achievements, and social stigmas as they coped with bullying and discovering who they are in the world.

I now want to make work about our journeys, with them, through them. I want to reclaim what was lost, show our human frailties as positive encounters that make us rounded and empathetic people. I want to demonstrate that the most important thing I have ever done in my life, can create stories, inspire art that can be shared: the good things and the bad things.

~Ruth Fabby

As a recent immigrant to the United States, my ideas of motherhood were very different from the motherhood practices of American women, although my ideas of disability were similar to the disability rhetoric in the United States. After having my first child, I began to experience significant *Deafness Gain* (back then I called it Hearing Loss). I was in complete denial and resistant to it. Growing up with my own mother’s hearing loss, I was aware of the difficulties that she experienced in her interactions with the world, including family. I was also keenly aware of the ridicule that she endured because of this. When I became a mother myself, it was not easy to reconcile that part of my identity. As an assimilating immigrant, I wanted to become the mythical perfect-looking, tidy, never late, gourmet cook, laundry-always-folded, family administrator, American mother. In my community’s world, this was not possible if one was D/deaf. So, I begrudgingly wore hearing aids, selecting the most inconspicuous ones to mask not only the device but my deafness.

In 2010 when my sons were 10, 7, and 3 years old, I walked out of a 5-minute shower with my bathrobe and head towel expecting to see my children focused on SpongeBob SquarePants, of course without hearing aids. As I expected I saw all my children focused on the TV, but I also saw an adult stranger standing in the room. She had her hand behind her back, I assume to exhibit passive body language. She saw my shocked face and raised her hands as if she was surrendering. I quickly wore my hearing aids explaining to her as I put them on that I was Deaf and couldn't hear without them. When it was apparent, I was ready to communicate, she explained that my 3-year-old had let her in when she knocked at the door.

I was fortunate to live in a quiet suburban neighborhood tucked into a hill off a busy road. We rarely got uninvited visitors. The woman that my son let in? She was delivering hoagies I ordered from the local high school band's fundraising event. It was that incident that sparked my journey as a deaf mother and a hearing dog partner. It also helped me tune into my children's disabilities.

I often say that I did not fully emerge as an artist until I became a mother. When my art practice was changed by motherhood, I began to find ways to incorporate my motherhood in my practice. This included the participation of my children in my projects, art about breastfeeding and other caregiving duties. My work in disability arts came later. I was working at Carnegie Mellon University as the Digital Arts Studio founder and manager at the School of Art when I was approached by the Western Pennsylvania School for the Deaf in Pittsburgh to create a STEAM (Science, Technology, Engineering, Art, and Math) curriculum modelled after the Digital Arts Studio (now Digital Print Studio). I was excited about the new challenge to create a program for a Deaf School but my experience with K-12 students and Deaf Education and Culture was nonexistent. I was surprised at their insistence and decided to take on the challenge. The experience at WPSD was in itself an education. I learned about Deaf Culture, Deaf Art, ASL fluency, and was welcomed by a warm and helpful community that augmented my identity. The Deaf Community's struggles were now my struggles, and their victories were my victories and it showed in my work. Yet the multiplicity of mother-Deaf-artist had still not emerged. The realization of this is bothersome and it was with conversations with Ruth that I knew this had to change.

~Fran Flaherty

Maternal Identity in Art

Maternal Identity is a complex one. The discussion of maternal identity in Art is even more so. The complicated subject of motherhood and other issues such as feminism,

race, and religion weaves a multifaceted, confusing, self-contradicting web. In this paper, we will briefly discuss maternal identity based on the recent and ongoing events of the Coronavirus Pandemic.

There have been numerous articles published in the *New York Times* regarding the state of Mothers during this pandemic. Articles called “The Primal Scream, ‘The Plight of Women in the Pandemic, and ‘They’re Tired as Hell and Just Can’t Take It Anymore.” The evidence is clear: Mothers in the United States are being disproportionately burdened during the pandemic. “American mothers are doing the most of the increased amount of child care and domestic work.”¹ One measurement of this according to Michael Madowitz, an economist at the Center for American Progress said “Just before the pandemic hit, for the first time ever, for a couple months, we had more women employed than men, and now we are back to late 1980s levels of women in the labor force.” The article goes on to say that the economic disaster of the pandemic is directly related to maternal stress levels, and by extension the stress levels of American children. In this 900 word article, the word mother appears 30 times and the word work and words referencing work appears as much. Motherhood is synonymous with labor: labor from childbirth, labor of domestic duties, labor for the economy, all the while modeling ourselves after blissfully happy, archetypal wife/mother/homemaker like June Cleaver. However, as Stephanie Coontz points out in her book, *The Way We Never Were: American Families and the Nostalgia Trap*, “contrary to popular opinion, ‘Leave it to Beaver’ was not a documentary.”²

The relationship of the lived experience of maternal themed art and the artworld is not a smooth one. Motherhood and caregiving themed art are rarely seen or given a platform. Furthermore, mothers are not expected to be artists. In 1968, the 29-year-old pregnant Mierle Laderman Ukeles was in the middle of a sculpture class at Pratt Institute when her male professor declared (as Mierle narrates) “Well, Mierle, I guess you know you can’t be an artist now.’ And I thought, ‘What are you talking about? I wanted to be a mother; it was a great blessing. But I was in a panic that it meant I couldn’t be an artist.”³ She went on to become one of the most important conceptual artists of our time and a leader in the feminist art movement.

¹ <https://www.nytimes.com/2021/02/04/parenting/working-moms-mental-health-coronavirus.html>

² Coontz, Stephanie. *The Way We Never Were: American Families & the Nostalgia Trap*

³ Liss, Andrea. *Feminist Art and the Maternal*

Disability Identity

The stigma of being disabled is still very rampant in our culture. Though *ableism* has made its way to Wikipedia and became part of the list of oppressions to fight against, we still see people with disabilities as unappealing burdens to society. A short search on social media indicates that disabled *influencers* (disabled people who use their disability to create social media content and amass a large audience) open themselves to a slew of hateful trolls (bullies) who choose to watch this content, judge, and express their distaste. Despite this, disabled influencers use these comments to strengthen their disability identities.

Disability identity refers to possessing a positive sense of self and feelings of connection to, or solidarity with, the disability community. A coherent disability identity is believed to help individuals adapt to disability, including navigating related social stresses and daily hassles. *Laughing at my Nightmare* author, Shane Burcaw and Dana Dunn, wrote in 2013 that “Disability identity is presumed to be an important and adaptive psychosocial construct in the lives of many people with disabilities, yet there is a paucity of scholarly research on the topic.” They continue by defining six key themes of disability identity: communal attachment, affirmation of disability, self-worth, pride, discrimination, and personal meaning. Any and all combinations of these themes are experienced with one’s disability identity. In fact, there is usually one key trait that is highlighted. In *Disability Identity: Exploring Narrative Accounts of Disability*, Dunn and Burcaw chart six different narratives of disabled people. Only one of those narratives included all six themes. These themes are drawn from studies of disability studies and rehabilitative psychology. They make the conclusion that “disability identity can inform future efforts aimed at exploring the psychosocial influence of disability.”⁴

In 2010, Tobin Siebers published *Disability Aesthetics*. In this book, Siebers narrates themes of disability throughout art history. From Odysseus’ Scar to Andy Warhol’s 1963 Orange Car Crashes 14 Times, Siebers argues that disability has been and should continue to be part of our understanding of beauty and humanity. The notion of disability aesthetics in art helps raise questions about the idea of what art was, is, and should be.

⁴ Dunn DS, Burcaw S. Disability identity: Exploring narrative accounts of disability. *Rehabilitation Psychology*. 2013;58(2):148-157. doi:10.1037/a0031691

Practicing Maternal Disability Art

“Disability Aesthetics in art is presented to be useful to art historians and critics and to anyone interested in matters of aesthetics in any conceivable medium, period, or genre. The great achievement of this book is its successful argument for the centrality of disability to any consideration of art.”⁵ It would be ideal for every art history class in colleges and universities to draw readings from this book to understand the role of disability identity in the aesthetics of artwork. We have yet to see a class beyond the curriculum of disability studies to include such texts. While core curriculums aim to continue our understanding of the fundamentals of math, science, and humanities the idea that disability identity can create a valuable perspective of core studies is lost.

In 2006, Jess Dobkin premiered *Lactation Station* in Toronto, CA. A performance piece that asked gallery attendees to sample pasteurized breast milk from five different donors. A decade later in 2016, after two miserable losses for women, the 2016 US presidential election and Brexit, Miriam Schaer writes that “Politically and culturally, gender and maternity still count, and even today breastfeeding is usually only acceptable if discreetly hidden so as to not offend.”⁶

Maternity and Disability have historically endured scrutiny in art. It is difficult to take on one or the other in an artist’s practice but to combine both might be artistic suicide. *Anthropology of Motherhood* has been described as a “radical exhibition.” We live in a time where the incorporation of caregiving in art is unusual, outsider, and rebellious. Teetering on sentimental art, art about the Culture of Care can be seen as corny, mushy, therefore not considered a credible subject. Disability arts is also considered outsider art. The depiction of the loner-genius-artists excludes people with disabilities not because they don’t exist, it is because we think that loneliness, independence, and “genius” are associated with good art and the perception of atypical, diseased, incomplete body could not be anything but an incapable ward. It’s no wonder why there is a lack of representation of this subject. The duality of disabled mother and disabled artist is too much to bear for anyone yet, it is carried by the hands of the people who are already overburdened while being deemed less, incomplete, not normal. We do, however, exist and the need to record this narrative is imperative to the survival of our humanity.

⁵ <https://dsq-sds.org/article/view/1579/1551>

⁶ <https://www.mamsie.bbk.ac.uk/article/id/4263/>

As the 2020 Coronavirus pandemic showed us, we are now, more than ever, interconnected. As we experience the need for care due to the Coronavirus, we are reminded of the foundations of survival and our vulnerabilities as humans. Maternal care perpetuates survival of our species and we need to understand that we carry those gestures and habits of care throughout our lives. It serves not only our own families but in all interactions: environmental or personal. Our survival will depend on our compassion and ability to care for one another. In her blog, Leaving Evidence, Mia Mingus instructs: *“We must leave evidence. Evidence that we were here, that we existed, that we survived and loved and ached. Evidence of the wholeness we never felt and the immense sense of fullness we gave to each other. Evidence of who we were, who we thought we were, who we never should have been. Evidence for each other that there are other ways to live--past survival; past isolation.”*⁷ Where do we record the stories of disabled mothers, the truth of our existence? How will the next generations learn from us if we don’t leave evidence? Unlike archeology, where artifacts are left behind for us to hunt, we have to consciously create our narrative. This is what will create our identity. To say that we existed, and created, not in spite of our disabilities but because of our disabilities. We are better artists, mothers, teachers, cultural producers because of what our disabilities provided us: humility, compassion, and the tenacity to survive against socially constructed odds.

We need to challenge institutions and leaders. How will you be part of this narrative and what legacies do you intend to leave the children, yours and ours. This is a call to action to be proud of our disabilities and our motherhood. A call to action to leaders and institutions to provide financial support and time and space for disabled mothers to tell their stories. This will allow us to share new and exciting things about our experience, to realize the beauty and the power of our lived experience.

⁷ <https://leavingevidence.wordpress.com/>