

**2021 03 28 – The Paper - RF**

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

Fran and Ruth: disabled artist-mothers 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.

Fran and Ruth 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?

Fran and Ruth will share with you a dissertation on why we as disabled artist-mothers do not represent these issues in our work and 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?

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**Ruth:** Hello Fran – how are you today?

**Fran:** I am fine – [baby cries off camera]

**Ruth:** The baby's crying?

**Fran:** What?

**Ruth:** The Baby's Crying?

**Fran:** Pardon me?

**Ruth:** [ pointing getting worked up] ...the baby's crying?

**Fran:** What are you pointing at?

**Ruth:** [ animated in sign] the bloody baby's crying?

**Fran:** What, where – not sure what you are pointing to?

**Ruth:** Totally mime – crying baby

**Fran:** oh, just a minute the baby's crying?

[Both Look exasperated]

## **Fran:**

Hello, I am Fran Ledonio Flaherty – an artist, educator, activist, promoter of women’s rights, Mother & Grandmother. I was born and raised in Manila, Philippines and immigrated to the US in my young adulthood and have been living in Pittsburgh, PA for 30 years. I am a proud Asian American. I have short black hair, black eyeglasses and am wearing.....

## **Ruth:**

Hello, I am Ruth Fabby performer, Artistic Director and programmer, I am from Liverpool UK, and currently live in Conwy a beautiful walled castle town in north Wales. I am a disability activist and a Mother of three. I have long dark hair, going grey, in my early 60’s, I am white woman and wearing glasses and a green top to show off my Irish roots.

## **Fran**

We are often dealing with multiple and conflicting tasks, in our lives as artists: time to think, develop and execute creative ideas, plus all the domestic duties in life. In 2015, I started Anthropology of Motherhood, an ongoing social practice art project and living archive. AOM elevates the act of caregiving through fine art by transforming mundane objects of caregiving into valuable art pieces such as paintings, sculpture, performance art, and mixed media pieces. AOM explores

and amplifies Disability Arts and the aesthetics of caregiving as an artistic practice focused on Human Centered Design 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 labour with the mission that societies should lead through gestures of care (rather than competition) as a necessary grounding and reorientation.

When I invited my good friend, Ruth Fabby to speak at one of our events, we were disappointed to realize that there was a gross lack of representation in art that combined maternal identity with disability identity. We are asking for your help to change that.

### **Ruth:**

We will illustrate this through sharing our stories that demonstrate how the negativities we experience impacts the way we make art.

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, I 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.

I will illustrate this with my first experience of pregnancy. 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!

Once my child was born, I was so scared of being thought of as not coping, that I almost died with a post-partum haemorrhage through fear of speaking out.

When the health visitors came to see me, they would check and scrutinise everything about how I was, what I ate, drank, was I coping or not coping. It felt intrusive not supportive, and I gained the sense that they were wanting me to fail.

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 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.

Yet, I was a damned good Mum: they learnt that life is not a perfect bed of roses and that our flawed bodies or senses doesn't mean we cannot live effective, fulfilled and constructive lives. And yes, I have brought so called, 'flawed' beings into the world. All three are my pride and joy, making their independent ways in the world. They each live with different impairment issues, from a mix of clinical depression, deafness gain, neuro-divergency and bi-polar.

## FRAN

While here in 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.



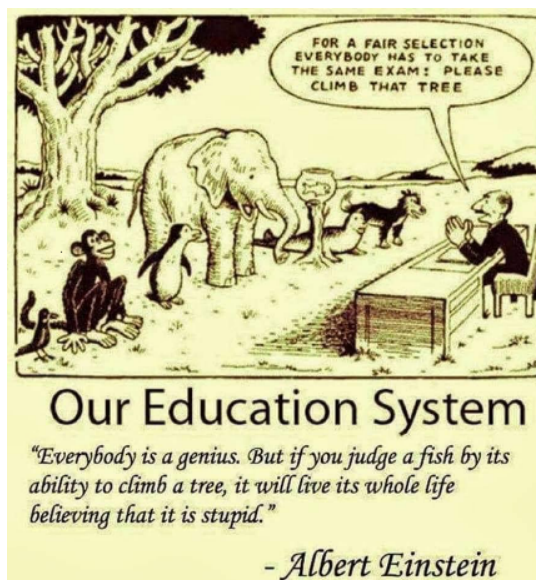
In 2010 when my sons were 10, 7, and 3 years old, I walked out of a 5-minute shower with my bathrobe and head towel expecting to see my children focused on SpongeBob SquarePants, of course without hearing aids. As I expected I saw all my children focused on the TV, but I also saw an adult stranger standing in the room. She had her hand behind her back, I assume to exhibit passive body language. She saw my shocked face she 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. The story has a rather benign ending, not something I would like to take up time, but I will leave it to your imaginations.

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.

## RUTH

It was tough when I knew my children had different impairment issues – neuro-divergency doesn't just run in my family – it literally gallops, but to experience how their various schools misunderstood and judged them and the pressures of a curriculum that pushes people into a one size fits all achievement level – is tough going.



Plus, I never had any access support at the parent's evenings or the school events – but I was always ready to fight for my children.

## **FRAN**

My identity as a mother came naturally to me. I was ready to be the caregiver for my children. My identity as an artist or creative practitioner was also an inherit trait. My identity as a Deaf and Disabled person took some work, some cultivating with a compassionate community. The acceptance of deafness gain, was only the beginning of my journey to meld my identity as a mother and a Deaf person. Though I was aware of my mother's disability all my life, I was not aware of Deaf Culture, more specifically, I was not aware of Deaf Art. As I began to accept my Deaf identity, I became aware of the complex, yet rich and exciting Deaf community. I experienced this duality: Mother-Artist and Deaf-Artist. With all my work and research about motherhood in the arts and the Culture of Care, the concept of Deaf-Mother-Artist did not take shape in my artwork. Strangely, I was an advocate for mothers, Deaf people, and artists, but the idea that I could embody this multiplicity was as lost to me as a drop of water in the sea.

## **RUTH**

Feeling successful as a Mum took a long time for me. I was so bound up thinking I would damage my children. I thought not hearing them cry or fearing they may have an accident and I wouldn't know, would be the worst thing ever. I had to face my demons and reflect



on how my own childhood was abusive, negative and stigmatised. There was a time that I honestly thought I should end my life, especially when my daughter was around 2 as I held an all-consuming fear that I would act like my own deafened mother. She struggled as a mother and did extremely harmful things, not just to me, but my brother and sister too. I was scared I would be just like her to my little girl. I only recently discovered that when I was first diagnosed and given hearing aids, my mother admitted that she was deaf too and also began to wear aids. I now wonder if the shame she felt was transferred onto me as a child. Interestingly, I didn't have these feelings of failure after my son was born.

There came a point where I had to face my internal issues, and once I started to gain strength, I openly declared to a roomful of sisters / women – that I no longer believed that I was a failure as a Mum. I now understand – I did a great job. Sure, my kids don't do what I expected them to do with their lives – but they are established and confident in making their way in the world.

## FRAN

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 non-existent. 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.



## **Ruth:**

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 a 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 – this was huge for me to do.

I more or less got what I fought for, because a student friend of mine happened to be on my labour unit at the right time. It was only later I found out he was hauled before a panel to give account as to why he didn't clamp the cord as instructed and followed my choices not theirs. I cannot thank him enough. Today, delayed cord clamping is common practice.



This paper came about because Fran and I wanted to explore what we have dealt with as disabled mothers. Our birth experiences have been difficult even when we have provided birth plans and GP letters of support. Being hands on Mums has also caused issues in how we were spoken too and treated. We both experienced intrusions into our parenting roles and dealt with a raft of issues in school: it is so tough to be fully present when your access needs where ignored time and time again.

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 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.

The relief I feel that the gift of life I choose to hold onto, has become the joy of my life.

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.

**FRAN:**

**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.**

**~Mia Mingus**

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

In a brief informal survey of Disabled Parents, only 11% of Disabled Creative Practitioners said they make work about their roles as caregivers. Of that number even less are given a platform to show their work. What can we do as, institutions, arts administrators, and artists to make certain that Disabled Caregivers “leave evidence” of our lived experience?

**RUTH:** We have lain bear our experiences: our motherhood, our joys and our pains. The challenge

now is to allow artwork and expressions to - forgive the pun - be birthed. Using frameworks such as the social model of disability and exploring how the disabling systems place us into the position of otherness that impacts us throughout our lives, this needs calling out. Art is how we do it.

Fran, the baby is still crying.....

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