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**“It’s Not About Me”**

A Multidisciplinary Oral History Solo Memoir Performance and Reflection Paper on the  
Responsibility of Listening

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**Abstract:** This paper is a reflection on a Multidisciplinary Oral History Solo Memoir Performance of a personal narrative of a woman—myself—sharing an experience of what it means to be disabled, walking around with an “invisible bruise.” The following paper reflects on that performance, as well as on the importance for oral historians to continue to establish more creative listening practices in order to bring the work beyond the archive. Creative listening practices that cultivate space in order to *hear* responsibly furthers potential for dialogical engagement. Original performance exhibition can be viewed here: <https://its-not-about-me.com>

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For a Columbia University Oral History graduate school thesis project I presented a solo performance centered around my experience of healing, both physically and emotionally, from more than a dozen central nervous system injuries. In the piece, through a hybrid performance utilizing the Zoom platform, as well as an in-person studio space, I shared what I discovered healing to be and not to be after seven years. Over the course of the performance I discussed what I uncovered on my journey and how I realized that my personal recovery could have looked very different if I stopped chasing the past version of myself sooner, and instead softened this aggressive pursuit by accepting the body that now exists.

What I share in the following pages, however, is less about my personal story and performance piece and far more centered on creative oral history practices found through my work that both troubled and broadened what oral history entails. Through this broader discussion within my performance piece I invited the audience on a journey with me to consider what is provided to one another and our community when candid stories are shared. This last piece was an integral part of my healing process because at the end of the day, I truly believe it was the transformative power of others sharing their stories, or even their witnessing of my own, that allowed me to persevere another day, even when it felt as though all odds were stacked against me.

Navigating how to share a personal narrative about health and recovery through the lens of oral history has felt sacrilegious at times. The traditionalist in me wanted to preserve the integrity of the field, as what I had initially considered to be oral history was a practice steeped primarily in the documentation of another person's story, not my own. For this reason, I have often thought to myself, "what kind of oral historian must I be if I am to share only my story, and what purpose does this serve?"

Through discovering various forms of oral history-art-based practices, my performance project challenged my own beliefs around "authenticity" and truth, as well as the meaning of "tradition." What I have come to understand from my own inquiries around each of these concepts is that oral history has various deviations from the original roadmap that Allan Nevins—the Western "grandfather" of the field (Kerr, 2016), as well as the American historian and broadcaster Studs Terkel who has been identified as another forefather—had initially laid out for its practitioners. Through excavating the traditional origins of its Indigenous roots, however, I now know that the documentation of stories can evolve from both another's as well as one's own sharing. Moreso, the way in which stories can be delivered is multifaceted and endlessly innovative, as we as oral historians constantly learn and reorient to what makes a story reachable, accessible, and appropriately heard.

I have been fascinated with how we move stories from archival spaces and two dimensional platforms, such as websites, into the public sphere for people to gather in proximity to one another while engaging in practices of listening. As a society we have needed to coexist with one another in order to evolve appropriate mechanisms for communication around food,

reproduction, and community needs. Therefore, it is my belief that in order to continue in a direction of intellectual evolution, we must also work toward cultivating shared spaces to gather and to learn from each other through the exchange of stories. Performance mediums such as plays and in-person presentations have historically served this very purpose, providing opportunities for interactivity and direct exchange. Stories have felt incredibly purposeful for my own healing in the way they have often provided a sense of belonging and interrelatedness, even when the experiences shared differ from my own. It has been the opportunity to establish a common ground of the trials and tribulation of human existence through the power of story that has reminded me that I am not alone in my struggles.

As both an artist and a healer, I live for the spontaneous combustion experienced by way of in-person emotive resonance and interactions that give preference to the biochemical and somatic response to one's narrative. It is the response of the welling-up of tears behind one's eyes, the blushing of cheeks, or the wordless solidarity expressed by placing a hand on one's heart that are all the gestural reactions that show why I find stories to be so deeply transformational. In a similar vein, composer and professor Sandeep Bhagwati writes in his article *Lamentations: A Gestural Theater in the Realm of Shadows* (2014) that "we cannot keep our hands, eyes, shoulders, neck still when we tell the story of our life" (77). I believe the same can also be true in not only the telling, but also upon listening to the narrative of another.

I have begun to understand that the Indigenous roots of oral history practices are very much about this form of exchange, the exchange of an experience shared from one body to the next, from one generation to the following, rekindled and stoked by way of its passage both through

story and time. The more I listen, the more I find myself believing that perhaps “stories”—the intimate narrative extended from one to another—are quite possibly the only seeds of “truth” that exist. It often appears to be the personal truths that provide meaning to one’s life, involving one’s relationship to belonging, kinship, and purpose. In a culture inundated by headlines disclosing information about the world's political and social conditions through alarming and triggering verbiage and soundbytes, I have to constantly remind myself that what lives behind it all are simply people in the ongoing pursuit to give meaning to their own, as well as others’ existences by way of the various iterations of story that constantly evolve from our personal and collective forms of meaning-making.

The gift that a story provides is a window into a life. My own oral history solo performance memoir, “It’s Not About Me,” was a way to provide such a window into a personal experience, in hopes that perhaps it could be illuminating for others on their own journeys of healing, wellness, and recovery. While initially presented in the format of a digital exhibition, with options to navigate between the reading, listening, and video documentation of the story being told, the method that I was more interested exploring was the embodied vocal delivery of the eventual live performance. I chose a performance because I wanted to bring a narrative, removed from the archive, into a space that was held in unison by others. I believe that shared spaces where people gather are the engines for new ideas to be both provoked and transmitted off the page and into the consciousness of a people. This is what cultural theorist Grant Kester discusses as a form of a dialogue of aesthetics, where he argues that a commitment to dialogical art “creates meaning for the various participants to speak, listen, and respond to” that uses face-to-face encounters to promote democratic engagement (2004, 85).

The possibility for moving ideas into the social organism of a community of people is communications researcher Heather Davis's primary focus in her dissertation "Art that Loves People: Relational Subjectivity in Community-Based Art Practices" (2011). Davis explores the social and political implications of community-based art that involve the collectivity of other humans by researching three artists who use in-person methods to communicate an idea to a collective. Through studying these artists' work, and using the ethnographic practice of friendship as a qualitative methodological approach to researching the relational outcomes of in-person encounters, Davis found that art focusing on in-person engagement yields an important unfolding of conversations among a group.

Through the framework of friendship, Davis found the mediums of interactivity the artists used that cultivated a frame for "humans to come together differently," provided another way to think about relational subjectivity (143). With these findings, she began to view friendship as offering a similar "open-ended structure" to that in which the exhibits cultivated, "one which resonates between people, an ethics of love which destabilizes the self, moving beyond itself to become inhabited, but also responsive, to others" (143). Davis discovered that the ideas exchanged after being exposed to each of the artist's works allowed the communities "to imagine and build more livable futures" (197), creating space for the "possibility of flourishing" (198). Davis further concluded that it is the "presence, pressures, and force of other humans" within a shared space that is radically generative (199).

The use of a live in-person oral history solo performance to represent a personal history of my own was an attempt to breathe life into a written narrative. Additionally, the shared space I created for others to hear my story was done so in order to foster meaningful dialogue among an audience, in hopes that it could be generative for conversations around relationships to body, self, and the larger social structure that provide their conceptual genesis. However, this was admittedly challenged by the limitations of Zoom. The narrative I shared, which toggled between healing and acceptance, was to bring into the collective a sense of personal interiority, by way of a candid and vulnerable share—believing that opening up in public about an intimate experience could not only yield trust in the space created, but also give opportunity for others to discuss their own meaning-making around personal challenges. I truly believe it is only through community and togetherness that we are able to heal. For this reason, I was hoping that such disclosure would potentiate a supportive and constructive space for hearing another’s constraints and limitations. Believing that in doing so, the conversations that ensued could further support those that might feel isolated by a disability or health conditions.

Although I had originally hoped to create a space for people to be in dialogue with both myself and others following my performance, due to a mismanagement of time—along with having to navigate an unforeseeable Zoom variable— I did not facilitate the appropriate forum needed for building out an intimate dialogic exchange post-presentation. In further reflection, in addition to this negligence in time management, I am curious if the post-performance dialogue could have potentially unfolded differently if each participant had been in the same room with one another rather than a majority of the audience in the virtual sphere. I would have liked to witness the

in-person pressure that may have been placed on the audience to engage if a physical space was present for everyone to do so.

Indigenous scholar Betty Bastien explores something similar in her book *Blackfoot Ways of Knowing: The Worldview of the Siksikaitstapi* (2004). Her work creates a public space that both shares her personal 'homecoming' of outwardly reclaiming her Indigenous identity, as well as opens up opportunities for others who might have similar conflicting identities such as her own, one that she expresses as the divide between Indigeneity and the spiritual practices of their ancestors and the academy, in hopes to possibly work toward building bridges within the following generation. It is by way of her story that she creates a vulnerable and constructive space for new belief systems to be built around spirituality within the institution, providing an argument for needing to find a merge of the two in order for her community to truly be seen and whole, and as a result heal. Additionally, she expressed such bridging as vitally important to yield a sense of purpose for future generations not to feel as though they are constantly straddling between two belief systems, one of which is marginalized to the dominant culture not representative of their inherited practices and traditions.

To do this she discusses the purpose that the story exchange provides between generations as “an opportunity for *Kaaahsinnooniksi* [our grandparents] to fulfill their roles and responsibilities to pass on knowledge to the next generation” (1). I find this to resonate with what disability activist Mia Mingus shared in her keynote speech at the 2018 Disability Intersectionality Summit, where she states “If we don’t share our stories, who will?”. I believe it is stories, both from past and current generations, that can serve the purpose of providing both structural and



spiritual support for others to find a sense of purpose, as well as solace, to collectively guide our ways forward, especially for those considered to exist within society's margins.

The margins resemble "precarity," a concept that Bastien speaks to in her own writings. The people of Blackfoot Tradition, as Bastien discusses, live a precarious existence as a result of colonial displacement and the genocide of her people and culture. In the continual recognition of their ability to persevere against such precarity, there is a practice of ending each prayer with the word 'Kaamotanni,' meaning "the survival of perils to live a long life" (127). While I am in no way comparing my own precarity to that of the Indigenous experience, as someone living outside of the conventional normativity and myself existing within the margins, I have my own relationship with the concept of 'Kaamotanni'. The precarity of survival in attempting to live as a disabled person within a culture dominated by normativity and abledness encapsulates much of my own existence, as I often have to navigate how to go about pushing back on the daily challenges in order to continue to live a life that I hope will be very long. Kaamotanni.

I have also been thinking more frequently about how fragility differs from precarity. Where fragility is generally in reference to the quality of a physical state, precarity is more cultural. Within my presentation I discuss how my disability straddles each of these, as being disabled lends itself to cultural and physical limitations. A culture that gives preference to neuro-normativity over that of the far broader spectrum in which human cognition generally seems to operate, pushes myself into the margins. However, where I find it challenging to resist the larger systemic barriers that I face in this precarious position, I believe myself to have far

more agency when it comes to my personal fragility, something I spoke to within my performance.

Through the adoption of the core tenets of willpower, self-determination, discipline, and gratitude, I have brought about a sense of agency in my healing process. In an effort to prevent myself from falling prey to victimization and defeat, I have continuously chosen to see the benefits of my scenario, finding ways to thrive and grow through all the uncertainty. Therefore, rather than identify as fragile, it has been by way of the recruitment of these tenets that I have instead chosen to function as “antifragile,” to use the Lebanese-American essayist and mathematical statistician Nassim Nicholas Taleb’s term from his 2012 book “*Antifragile: Things That Gain From Disorder*.” Taleb describes antifragility as things that benefit from shock and when exposed to such conditions—conditions that he describes as those which yield a sense of volatility, randomness, disorder, stress, risk, and uncertainty—are the very things that create growth. This growth, as he further elaborates, is beyond resilience or robustness, as “the resilient resists shocks and stays the same; the antifragile gets better” (2).

The first two years of healing from my own health condition, I adopted a mindset of fragility. I wanted everyone, but myself, to fix me—ranging from conventional doctors to spiritual healers. After reading copious amounts of books it suddenly dawned on me that I was perpetuating a cycle of dependency on sources that lived outside of myself in order to heal. In this recognition, I swiftly shifted gears and chose to see my injuries as an opportunity to work with the parameters that I had now been afforded to make sure I was continuing to live life to its highest potential, even if that potential now looked different. This is similar to Carolynn Myss's discussions on

“life choices” in her book *Sacred Contracts* (2013). She explains that we can choose to perpetuate hardship on ourselves and others through believing that our misfortunes were a mistake not meant to have happened, or we can view whatever accidents and misgivings we have had as a part of a *Sacred Contract* in each of our individual lives.

By making a choice to push back on my “fragility” I believe I have not only gone through a form of healing, but developmentally expanded both emotionally and spiritually in ways that I hadn’t known to be previously possible. Taleb and Myss’s perspectives, as well as Bastian’s writing focused on integrating spirituality into the academy, are all differing ontologies that I have subscribed to in order to find a balance between the two worlds that I personally exist in—one of deep-seated spiritual practice and another of intellectual critique, believing, like Bastian, that both can be held when more stories of disclosure and truths are shared.

It is also important to acknowledge that Taleb’s antifragility and Myss’s discussion of “choice” pads no one against a precarious existence, as they only work to support shifts in mindset for those who have existed in states of precarity. For disabled and non-normative bodies there still must be ample space not only for such precarious lives to be seen, but to also be supported within the dominant culture narrative of capitalism, a system that often makes very little room for such “dys”-functioning, allocating priority to highly functional productive-abled-bodied demographics.

As a healer I sit with people on a weekly basis and listen to stories. Stories that might have first to do with illness and disease, but through further excavation, are often buried in stories of

despair, grief, anger, lack of purpose, along with the inability to maintain the status quo that others appear to be maintaining on social media platforms. Those that I see that do have a diagnosed disability often ask me if they will get better. The concept of better— i.e. operating at a societal level considered to equate competence as well as the return to something that one was previously—appears to be the only conscious alternative to being “unwell” or “injured”. This exemplifies the lack of spiritual and intellectual options offered for bodies unable to return to such levels of normativity.

We have a culture that lacks spaces for people to be seen as functionable outside the range of the neurotypicality portrayed throughout mainstream media. I believe that not providing a broader range of stories limits what non-normative individuals are exposed to and, therefore, cultivates a further “lack mentality” or sense of incompetence, preventing personal growth and healing. If there were more images in our mainstream media culture of healing looking different from the full return to the previous version of self before a sickness, illness, or injury but rather the ability to continue to be seen as functional, and therefore acceptable within the constraints of that condition, I believe we would invite in a broader range of what wholeness entails, yielding ultimate wellness.

With all the stories I hear as both a clinician and oral historian, I have come to feel a sense of responsibility to be a conduit for such forms of social dialogue around wellness, ones in which we can welcome the totality of one another. Bastian’s attempts at broadening the spectrum of inclusivity—through her writings on the precarity of Indigenous existences and cultural erasure of the spiritual practices within academia—are concepts built into the foundation of my work as

well. I too ask how creative methods of listening can be used to responsibly hear stories of difference in order to take action toward cultivating a more inclusive world.

The digital archival space I created for the live performance was in effort to provide increased accessibility, acknowledge neurodiversity, and honor the various ways in which people assimilate information. It is for this reason my offerings included writing, audio, video, and live performance. Theorist and political philosopher Erin Manning in her book *The Minor Gesture (Thought in Act)* (2006) creates a captivating and intellectually rigorous critique on neurotypical perception. To transcend the neurotypical ways in which we often move, know, or relate, Manning uses the language of the *minor gesture*—“the gestural force that opens experience to its potential variation” (2)—to describe the nuances of human capacity to open to new modes of relating, experiencing and expressing. She believed that “it does this from within experience itself, activating a shift in tone, a difference in quality” (2). This relates to my desire to elicit such nuanced emotivity through the creative listening practices devised within my oral history performance work. My attempt to offer other ways of accessing a narrative, outside the mere iteration of the word, was to enable a somatic transmission from my body to others, in order for a “felt” sense of the narrative to be established.

The minor (the minor gesture), as Manning goes on to explain, exists in the margins of the major—the structural beliefs and performed identities our culture organizes itself around, determining a pre-existing value that everything else must align itself with in order to accomplish success. However, she also goes on to advocate that the “minor”, or the minoritarian tendencies, are actually what initiates conditions for change:

*“It [the minor]has a mobility not given to the major: its rhythms are not controlled by a preexisting structure, but open to flux. In variation is in change, indeterminate. But indeterminacy, because of its wildness, is often seen as unrigorous, flimsy, its lack of solidity mistaken for a lack of consistency. The minor thus gets cast aside, overlooked, or forgotten in the interplay of major chords. This is the downside of the minor, but also its strength: that it does not have the full force of a preexisting status, of a given structure, of a predetermined metric, to keep it alive. It is out of time, untimely, rhythmically inventing its own pulse” (1).*

Her poetic interpretation of alternative ways of experiencing and expressing gives gravitas to the way in which I relate, providing value to those that operate outside of the neurotypical range. Not only providing value, in fact, but also considering their presence necessary in order for such alternative ways of operating to push against, and make cracks within, our dominant culture’s operating system, providing change over time. Change that is evoked by inventiveness, thoughtfulness, and emotivity.

The emotivity of what I had hoped to cultivate is somewhat similar to what Manning identifies as a form of “autistic perception—the opening, in perception, to the unclassified, the uncategorized” (12). I believe that to have an audience somatically assimilate a story is similar to that of her concept of “autistics perception”, one that is the visceral response, understood beyond the intellectual digestion of its transmission, that is retained in a body long after its hearing.

It is for this reason that with the start of my own narrative performance piece I attempted to guide people into a space through visualization in order to establish both a sense of connection and belonging between self and others, as well as to create a space to receive the narrative by way of both mind and body. I hoped that this guidance assisted in supporting the listening practice for both the performance and a post-performance exchange, as well as alternative ways of relating to the material outside of the cognitive realm. The visualization I offered began with a

request for participants to trust me in closing their eyes and allowing me to navigate them through time and space into memories of the past that eventually led them to the current space that we had gathered that day. I verbally guided them to recall a time in which they had a memory of someone sharing a story with them that lived beyond their exchange, a feeling of the sharing that could still be viscerally recalled.

After allowing for a moment for this to simmer, I then asked for them to leave that particular memory behind and, with the eyes remaining closed, I had them visualize themselves walking into the room that I was currently in, seeing a table with food and drinks at which the others were gathering, and had them join. I went on to explain how they were perhaps initially hesitant to move toward a table of strangers, asking them to notice how over time though, through conversations and story sharing, there became an affection that built up, noticing now the “strangers were becoming less strange.” Eventually I guided them into the circle of chairs I had described as placed around me. Once seated, I attempted to anchor them further by detailing the feeling of their back against the chair and the warmth of the others in the space that they now had cultivated a kinship among. Upon re-opening their eyes, I had hoped that the nuanced viscerality provoked though the five minute opening visualization exercise allowed them to receive my story from a space of connection and solidarity with and among the others.

I believe the possible solidarity that is developed with shared listening practices also has the potential to inspire a sense of responsibility toward a group, extending outward to support a genesis in community care practices and stewardship. In Farinati and Firth’s article *The Force of Listening*, they inquire about what potential transformative power listening might facilitate,

bringing in elements of collectivity, solidarity, and resonance. They discuss how listening requires solidarity between two people in the example of an interpersonal encounter, as well as the solidarity of community (19). It is this sense of solidarity that I found to be present within the classroom when I shared my oral history performance memoir with my peers. The feedback included vulnerable disclosures from others sharing similar feelings of living with a disability or just personal challenges for which they found resonance within my story. This revealed to me once again the relationship-building quality that stories can have. This is what I had hoped to expand upon by utilizing an in-person event to showcase my story as a performance versus a two dimensional audio recording or written document living solely online. However, as mentioned previously, due to various variables and timing constraints, I was unable to foster the necessary space to facilitate the important dialogic exchange I had hoped would transpire after my presentation. This was a crucial learning experience to be workshopped in future events.

As much as listening can cultivate solidarity, however, it can also be fraught. The fraught nature of collective listening exists in how each person's hearing deviates from another, as no one person hears, or listens, alike. Oral history and applied theater scholar Luis Sotelo Castro, in his work *"Not Being Able to Speak Is Torture: Performing Listening to Painful Narratives"* (2020) goes into how, by way of turning the narrator and the public into "Performers of Listening" there exists a form of relational context, establishing a container for the stories shared within. This container provides an agreed-upon space to work through what is being exchanged, and most importantly heard, within the relationship cultivated between a storyteller and the audience wishing to be reached. Castro points out that what this relationship provides is a format in which any misinterpretations or misunderstanding, or "non-hearing" can be corrected (222).



Castro also points out that a space devised for such forms of listening “corrects the notion of the public being dis-embodied,” (227) from both one another as well as from the listener. Giving more attention to who listens encourages thoughtfulness around what context, purpose, and effect the listening will have on the people receiving the narrative being told. If a story is not responsibly heard, or does not access the most appropriate audience by which it is meant to be received, then the circulation of one’s narrative can be of little service or lead to an outcome that can potentially cause harm and perpetuate a feeling of violation (221). This was of particular importance in Castro’s work within the Truth Commission of Colombia with individuals who have experienced dehumanizing human rights violations. As he goes on to explain, sharing their testimonials with the Truth and Reconciliation Commissions multiple times and still not being heard is not healing nor does it lead to solidarity, but rather furthers resentment (222). This yields what philosopher Jill Stauffer frames as an experience of being abandoned by humanity, identified as that of ‘ethical loneliness’ (2018, 9).

By way of exploring the practice of listening, so integral to the field of oral history, through the solo performance I presented of my healing and recovery journey, I was able to understand the importance of cultivating the appropriate spaces needed for one’s story to be received, as well as to be of benefit both for the narrator and an audience. With this reckoning, I believe that in the future I will bring more intentionality into this aspect of the work by continually curating and fine tuning the necessary audience needed for my narrative to serve its cultural, social, and intellectual purpose. Castro’s work has led me to deepen my understanding of how integral this can be, deepening my understanding of the effect a narrative can have and not have on its

listeners. Similarly, in navigating how to represent my own story in a field of which I had previously only collected others, Bastian's work was a wonderful companion piece, continuously reminding me that through the sharing of our own stories we encourage others on their own paths of discovery, reckoning, and belonging. The cultivation of relationships in gathering environments in which our meaning-making is shared through story puts the necessary pressure on one another to make radical shifts.

So many of the shifts needed to be made within our dominant culture, however, are done so by outliers and thinkers who (dys)function within the margins, pressurizing a culture to shape-shift and adopt new ways of operating in order for alternative models of functioning to become more predominant. It is “variation that causes change”, as was illuminated in Manning’s “*Minor Gesture*” (2006), reminding me that while I, along with so many others, may have the daily experience of being neurodivergent minoritarians, it is our initially seemingly insignificant counter-existence to that of dominant culture that plants the seeds for the eventual fracture that leads to rebirths and cultural changes. These fractures have the potential, like an infection, to build a stronger ‘social immunity’ that involves more space for narratives of neurodiversity and (dy)functioning to be our normative models of rhetoric. This is how I believe Talib’s discussion of antifragility can be applied to our collective cultural evolution. The power of the story exists to acknowledge how others exist. By hearing how another exists outside our individual perceptions I believe we are able to cultivate a more inclusive and empathetic future that welcomes broader spectrums of what wellness, function, and being whole encompasses.

Telling stories for narratives to be responsibly heard also involves intentionality, agency, and openness to “not knowing.” I believe these to be a part of the core tenets of what is needed in spaces curated for listening in order for others to receive and hear the words, expressions, and messages held in the delivery quality of another’s telling. By creating intentional spaces for listening, collectivity, inclusivity, and interactivity for stories *wanting* to be heard, oral historians and listening practitioners can continue to develop offerings beyond the traditional archiving of narratives for more dialogical exchange to transpire, broadening the potential outcomes the field can have within a community of people. As it’s my belief that it is community dialogue that potentiates change.

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