



IMAG

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InSEA ART Education VISUAL Journal IMAG intends to provide a visual platform, which, in line with the constitution of InSEA, will help foster international cooperation and understanding, and promote creative activity in art through sharing experiences, improving practices, and strengthening the position of art in all educational settings. IMAG is an international, online, Open Access and peer-reviewed e-publication for the identification, publication and dissemination of art education theories and practices through visual methods and media.

Guest Editors: Alice Wexler and Mira Kallio-Tavin

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EDITORIAL

Alice Wexler

Mira Kallio-Tavin

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Welcome to IMAG #8. This issue is inspired by the recent work in disability studies and the arts, still in its nascent stage in most countries. We were particularly inspired to form the call for essays of this issue based on the work of Mia Mingus, a well-known disability activist and disabled adoptee from Korea, who encourages the notion that the disability identity does not exist in isolation, but rather co-exists with other identity markers, such as sexuality, class, gender and race, as well as the social and political impacts of societies—the ubiquitous “inequalities of socioeconomic and racial structures” (Connor, 2016, p. 496). Disability activists insist on their inclusion with other marginalized and oppressed identities, since they believe that oppression is what they have most in common within the highly diverse disability category. In this issue the guest editors advocate for a less restricted discourse about disability beyond the “multi-layered establishment” of special education (p. 494). As David Connor suggests, in a democratic society alternative ideas to established practices deserve attention. The art educators and artists in this issue offer a variety of ways these ideas can take place in the classroom, the studio, the community center, or on the stage. The authors also explore how art practices can help to inform knowledge of society and its institutions, which often are based on normative values and practices.

British theatre director and playwright Paddy Masfield (1997) became disabled in middle-age. He thought, that had he woken up Black or a woman he would have felt far more comfortable. That was how little he knew about disability. How much do any of us know (as abled people) about the life experience of disability? And yet, people who identify as disabled form the largest minority group in the world (WHO, 2019). And it is likely that many others experience non-normative bodymind during their lives. Therefore, the notion that disability touches only those who are labeled as “special” is a false idea. Given Masfield’s career in theatre arts, his attention turned toward how disability is made invisible or misrepresented by the non-disabled media. Instead, he found a vibrant community that crossed the barriers of age, gender, race, and nationality.

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The authors in this issue reflect the vibrancy of an international disability arts community by shifting the art made by the disabled artist from a form of inclusive education or therapy to an important cultural contribution. As Jennifer Eisenhauer (2007) noted, disabled artists in the school have been limited by the notion of institutionalized inclusion. Even within this well-intended practice, disability remains a de-contextualized individual problem rather than part of a rich human diversity. "Inclusionism" puts disabled artists in the circumscribed position of striving to achieve the level of their non-disabled peers. And thus they are defined as lacking and inferior, which leads to their exclusion from the socioeconomic and political structures that maintain the disabled bodymind in an outdated concept of human existence.

In the first essay, "on the relationship between joy and mental illness," Carol Zou's visual and poetic autopathography about her post-traumatic stress disorder is the result of what she calls the intergenerational trauma of a child of parents of the Cultural Revolution in China. Her inclusion of joy in the title is appropriate considering the positive shift from tragedy narratives to memoirs and autobiographies. In this visual memoir, as with others in this collection, Zou reclaims her illness in an exploration of her embodied self. With impressionistic black and white images of nature, places, and spaces, she explores the inbetweenness of living with both mental illness and joy. Thomas G. Couser (1991) calls the flowering of autopathology "a sign of cultural health—an acknowledgement and an exploration of our condition as embodied selves" (p. 65). He notes that the majority of these narratives are written by women. Coincidentally, all but one of the articles in this issue are written by individuals who identify themselves as women.

In "The Yellow Crayon: Rhetoricity, Mental Disability, and Art Education," Jennifer (Eisenhauer) Richardson writes a personal account of experiencing a diminished sense of self-worth within an institution. The yellow crayon becomes a metaphor and symbol for the low expectations of the "Other" by the "mentally fit" in a psychiatric

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section of an emergency room. In response to a most basic need, a pencil or pen with which to write, she was given a yellow crayon. Eisenhower Richardson writes, "When a woman with a disability is handed a yellow crayon with which to write, an assumption is made that both a woman and a person with a mental disability has nothing to say." The result was the use of the crayon as a creative tool and the writing of a poem of found text that expresses how people with mental disabilities are positioned as non-rhetorical, or not heard. Her images are close-ups of the creative use of a crayon, displaying the selected words, "voice," "word," "a lullaby breathing," on the surface of textured paper. She asks how often we, as art educators, have offered the equivalent of a yellow crayon to students with mental disabilities.

In the third visual essay, "Archiving Spaces: Walking, Murmuring, and Writing with Artist Nicole Storm," Min Gu follows Nicole Storm during her daily routine at the Creative Growth Art Center in Oakland California. Her routine comprises collecting and "archiving" incidental studio materials left on tables and desks, such as studio handouts, email printouts, napkins, and nametags. Storm's artwork is a collection of such memorabilia, which narrates her interests and attachments, especially to the staff at Creative Growth. Gu writes, "As such, Nicole's art practice constitutes archival performance," or the "archive as artwork." In her images, Gu shows Storm's artworks, and her journey around the art center. More importantly, the images unveil Storm's archival practice. Gu's visual recounting of Nicole's process also becomes an archival performance, and an archival encounter for the reader.

G.H. Greer's visual essay, "Clear Margins: A Portrait of Allies—A dialogue and a Map," explores the intersection between a visible and invisible disability; between a mother with cancer and a child with depression. The mother/child relationship, which has at times been fraught with divergent needs, is described through their dialogue. The non-fictional dialogue with Greer's mother and author Anne Bishop, creates an additional dialogue between Greer's "reality at

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the time” and their “aspirational self.” Greer writes, “By employing dialogue between reality and aspiration, and creating the conditions for serendipity, the author aims to move beyond the binaries of giving and receiving when it comes to care, inclusion, and conflicting needs.” Greer begins by unpacking the intent of Universal Design: what is good for some is good for all, and asks if the needs of some are, in fact, good for others. Their relationship with their mother becomes the entry point to examine such issues. Their phrenological illustrations of themselves and their mother depict the images that illustrated mental traits in nineteenth-century pseudoscience. By replacing the diagram’s labels with word associations, they use visual play as a form of resistance, create serendipitous poetry, and eventually step away from medicalized stigma.

In “not the epitome of normalcy,” Karen Keifer-Boyd describes a moment during her five years in Lubbock Texas in which she spotted the unusual appearance of a cloud in the perpetual blue sky. Her photograph of the cloud hovering over the landscape later became a visual narrative for the “White abled-bodied hetero-male [as] the epitome of normalcy in which all others are judged as lesser, as abnormal.” The constant arid climate and homogenous life forms of the desert become metaphors for enforced sameness at her University. The relief of sudden canyons that appear in a flat landscape is a reminder of diversity and difference, hidden within the University out of fear of marginalization.

“IMAGINE a Place Photographed by Those who Cannot See” by Noemí Peña Sánchez, is based on an exhibition and seminar with the Faculty of Fine Arts in Complutense University of Madrid. The project explores how both sighted and visually impaired people work together in a photographic interpretation of imagined places. The photographic narratives of the visually impaired were inspired by memories of places they had been, which were then interpreted by sighted people as a sensorial rather than visual representation. The dialogue that followed was then documented through the author’s camera. The images depict both the visual and tangible sources of

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inspiration for the memories, and moments of the dialogue between the participants. Peña Sánchez writes, "The author's interest lies in creating connections between time and what is visible through the camera."

"Seeing and Seeing Through: Negotiating the Intersection of Feminism and Disability," by Alexandra Allen, is a narrative autobiography that investigates feminism and disability as it intersects with the male gaze. Allen parses out the definition of the stare and the gaze based on Rosemarie Garland-Thomson's (1997) study in which "the gaze sexualizes the female form, whereby the stare is a way of looking at the disabled as a 'grotesque spectacle' (p. 285). Allen experienced the stare as a woman with mental disabilities and the male gaze as an objectification of her body as a young model. She visualizes these intersecting identities in a three-dimensional art work that describes the shifting context of social norms in which the female body is fetishized as either sexual or deviant.

In the final visual essay, "An Interview with Visual Artist and Body Positivity Activist Viola Thiele on Visible Hidden Disabilities," Nina Stuhldreher examines how "fatness," although in plain sight nevertheless resists the category of disability. Viola Thiele is a visual artist and activist in Germany who challenges "fat shaming" by performing as a "fat person," and thus insisting that her audience sees the world through her eyes. Stuhldreher writes, "This potential change of perspectives shows the productively disruptive power that disability studies can have, and should actually come with a trigger warning for art educators." In their interview, Thiele describes how her visible anomaly gives others permission to judge her and draw conclusions about her life. Her performance group "Mosh Mosh" which she calls "an electro-glam-fem-trash-performance duo" enables her to turn body shaming into a positive experience.

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on the relationship between joy and mental illness

每天我都記念我的神經病

Carol Zou

Independent Artist, U.S.A.

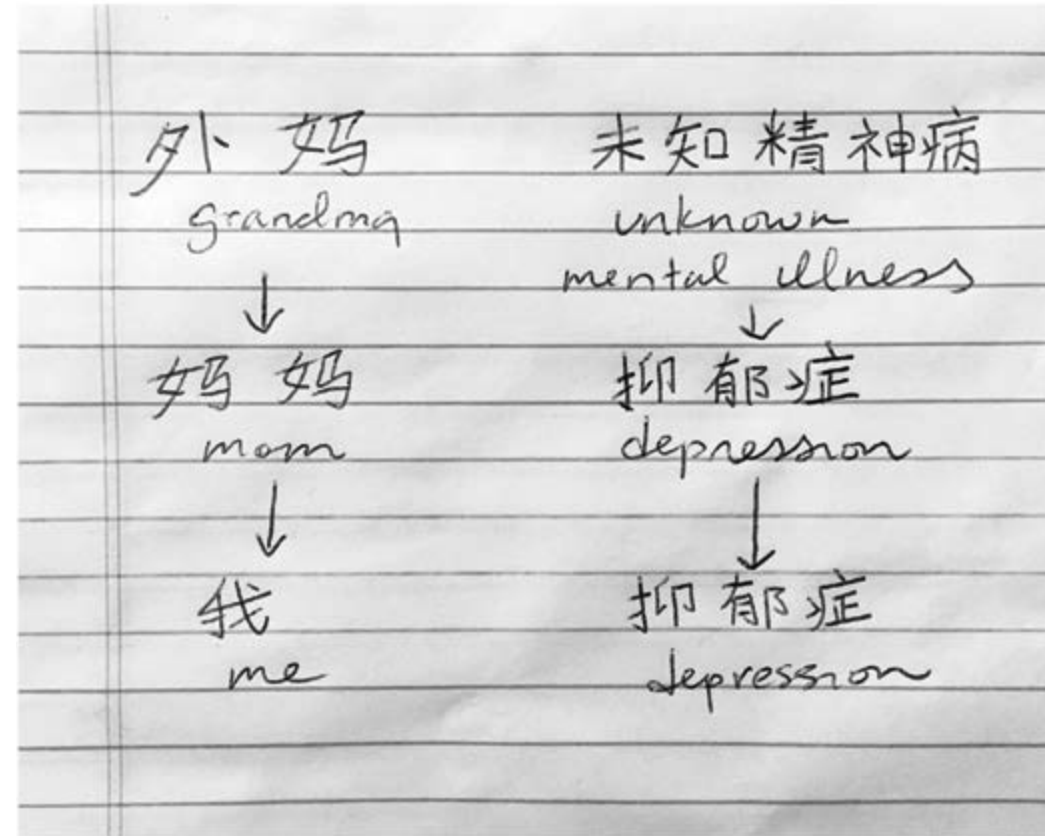
DOI: 10.24981/2414-3332-7.2019-2

Carol Zou is an artist, writer, educator, and cultural organizer who has worked for over a decade on the relationship between arts, culture, community, and activism. Her work has spanned various collaborative modes with: Yarn Bombing Los Angeles, Michelada Think Tank, Trans. lation Vickery Meadow, Asian Arts Initiative, U.S. Department of Arts and Culture, Imagining America, American Monument, and currently as the Enterprise Community Partners Rose Fellow with Little Tokyo Service Center. She believes that we are most free when we help others get free.



preface:

i have managed post-traumatic stress disorder for the entirety of my adult life, so perhaps i know something about mental illness. i have felt the water of intergenerational trauma undo my body like a recurring tidal wave, so perhaps i know something about mental illness. but i am also still alive, so perhaps i know something about joy.



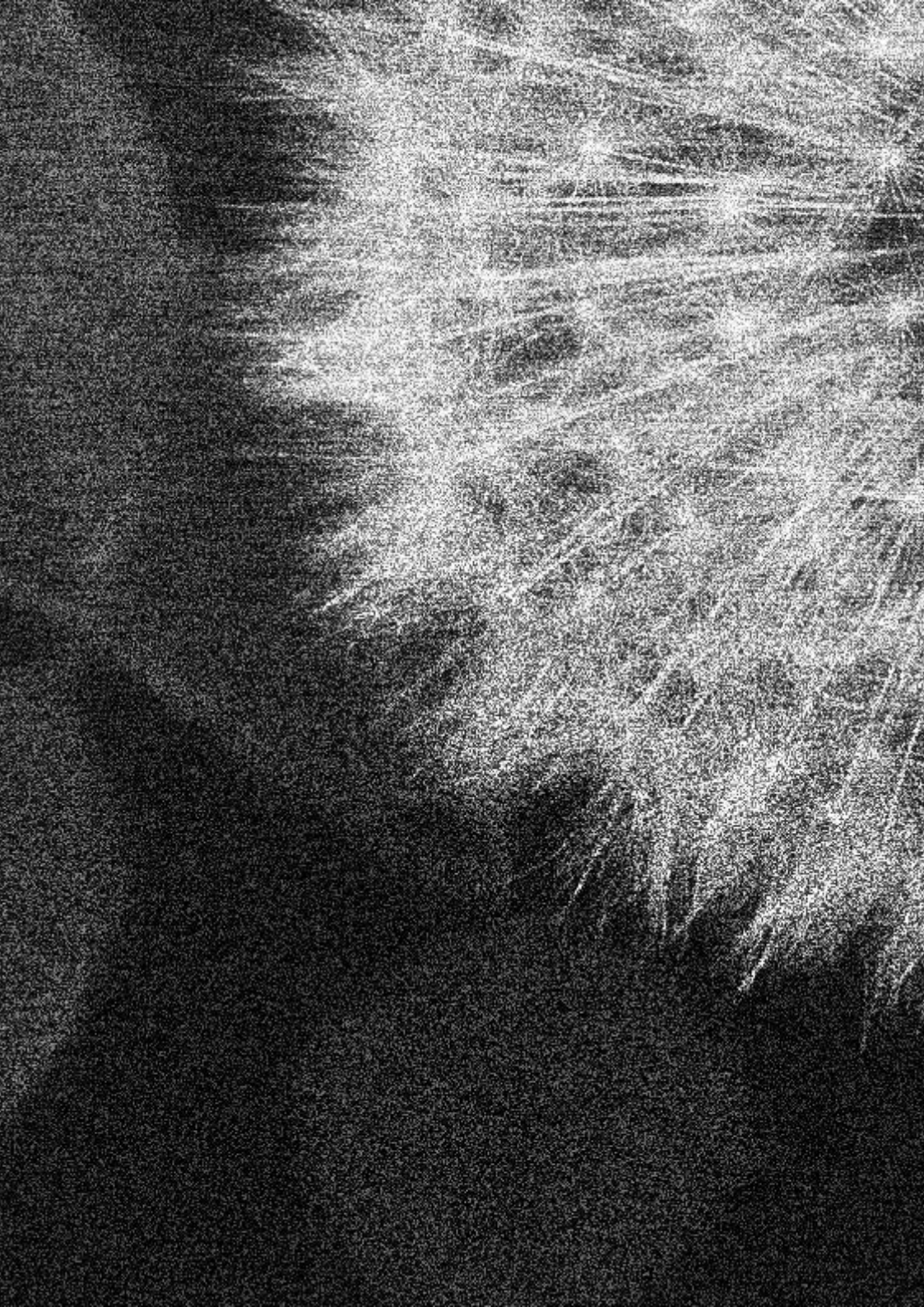
I.

mental illness feels like something eating away at you day by day. mental illness has been with you so long it is starting to feel like a friend, or at the very least, a security blanket that is faded and full of holes, and that you know you should give up but feel naked doing so. your body has been heavy with the weight of this uninvited security blanket for so long—are you truly ready to stand up without it? perhaps the way that you have learned to deal with mental illness is to hold its hand while keeping a safe distance. mental illness feels like self-doubt about the way in which you chemically relate to this world. there is a chronic window shade between your conscious memories and the world. you mistrust your perceptions.

mental illness teaches you how to be kind, how to hear others who similarly suffer, but more importantly how to receive them. mental illness teaches you the value of silence, which is never truly silent, but instead is a holographic shade of pensiveness, understanding, and resignation. mental illness makes you feel like a stranger; this is how you know you are mentally ill. mental illness' favorite location is absconding. mental illness is not public; when we pass someone who is mentally ill in public, we respond with revulsion. the feeling begins as revulsion at them, then it becomes revulsion at ourselves, and finally it settles into revulsion at the ways in which our body politic does not care for our bodies. we think if we don't see it, it doesn't exist; mental illness is a shadow. sometimes mental illness makes you feel like a shadow, and sometimes you wonder if others can love a shadow, or if their affections are only reserved for those who do not feel like a ghost. for you sadly suspect others around you are more alive.

mental illness is knowing that the veneer of everyday life routinely peels away into abysses. mental illness is bedridden, and bed is a kind place. mental illness makes no sharp movements for fear of relapse; mental illness is forever allocating the good days and weathering the bad days. sometimes mental illness feels like ice cubes in the pit of your stomach and sometimes mental illness feels like trying to hang on to a rollercoaster with your fingernails. mental illness lives in your body like a permanently scared animal, ready to run.

lately i've felt a desire to look at electronic scans of my brain, and to understand just how much of it is damaged. or maybe it's not damaged after all, and i would have to find another justification for my personality defects. symptoms of brain damage that i found out five years after the fact while collating informational packets on teen dating violence: impulsiveness, memory loss, increased risk taking. all the bad decisions, the personality defects, are suddenly viewed through a retroactive filter that wonders if you do, in fact, have a death drive. does it terrify you to have a death drive, or does it simply make life a little bit more exciting? there is a permanent sense of something missing, parts of your brain that have been removed by an ice cream scoop: your life on a permanent delay, your brain misfiring in brief, brilliant, abortive sparks like fireworks in the night or an overheating hard drive. biology class would term it as axons not touching their dendrites. axons not touching their dendrites.



II.

joy feels like those brief moments when you forget that you are mentally ill. joy is the dance floor, joy is loud music, joy is overwhelming your senses so that your brain is no longer shorting out in anxious overdrive but rather is subjugated to sensorial expression. your body, this joyous organ so capable of regeneration, so unconcerned with thought. melody rearranges molecules—and so you are convinced that perhaps for the length of a pop song, the trouble in your brain too can be rearranged. joy is breathing. joy is permissible screaming. joy is axons touching their dendrites.

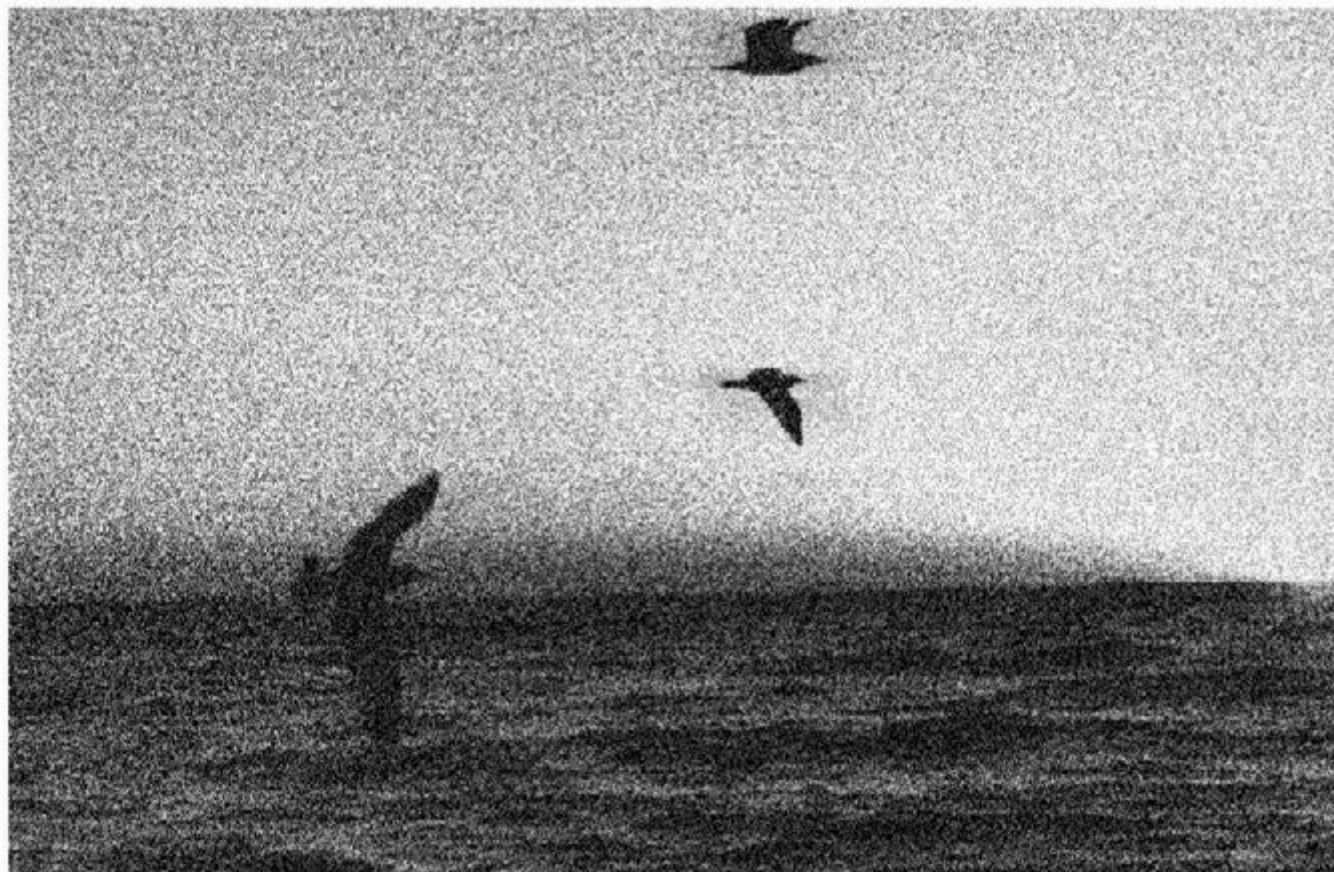
joy becomes political when you know what it's like to go for periods without feeling joy, which is akin to a body going for periods without love, touch, water. joy is deliberate when everyone around you has very few reasons to be joyful. joy is a response to futility; joy is laughter when there is in fact nothing to laugh at. joy says you will not give up; joy is your last resort and your last stand. joy is both a deliberate, precise forgetting of that which makes your body heavy, and joy is also a firm avowal and defiance. joy is running into your dear friend despair and deciding that it will not take you today. joy is quiet victory. joy is your heart stretching out so large that the thin mud fortress you have carefully sculpted around it cracks for a brief second. joy is your secret weapon, and you harbor a worn sympathy for those who do not know mental illness, but more importantly, also do not know joy.

joy in these configurations is fleeting, precious, a winking glint of sunlight before receding into the fog of everyday ache. joy is a firefly, and those of us who are used to it, know where to look and how to catch it. joy carries you through the way that a drop of water on your tongue carries you to the next waystation, at which point we again find it incumbent to repeat our rituals of conjuring joy and manifesting water.



III.

do you wonder if alternate realities exist, and do you long for them? i often ask myself this: if, out of all the different strands of temporal possibility, would i choose the one that doesn't feel like a permanent head wound? to say no is to be accused of fetishizing debility. to say yes is to treat yourself like one big regret. sometimes i would like to stand up and sing, unclouded. but i also know that on the other side of mental illness is resilience, empathy, and meeting others who are on a similar journey across the infinite chasm. i write this text as a love letter and a mirror, a way of meeting you, seeing you, and in that moment of recognition may we both find temporary solace. solace is that place beside the ocean, beneath the sunrise. the ocean is the mental illness and the sun is the joy, and i am the bird that flies in between.



The yellow crayon: rhetoricity, mental disability, and art education

Jennifer (Eisenhauer) Richardson

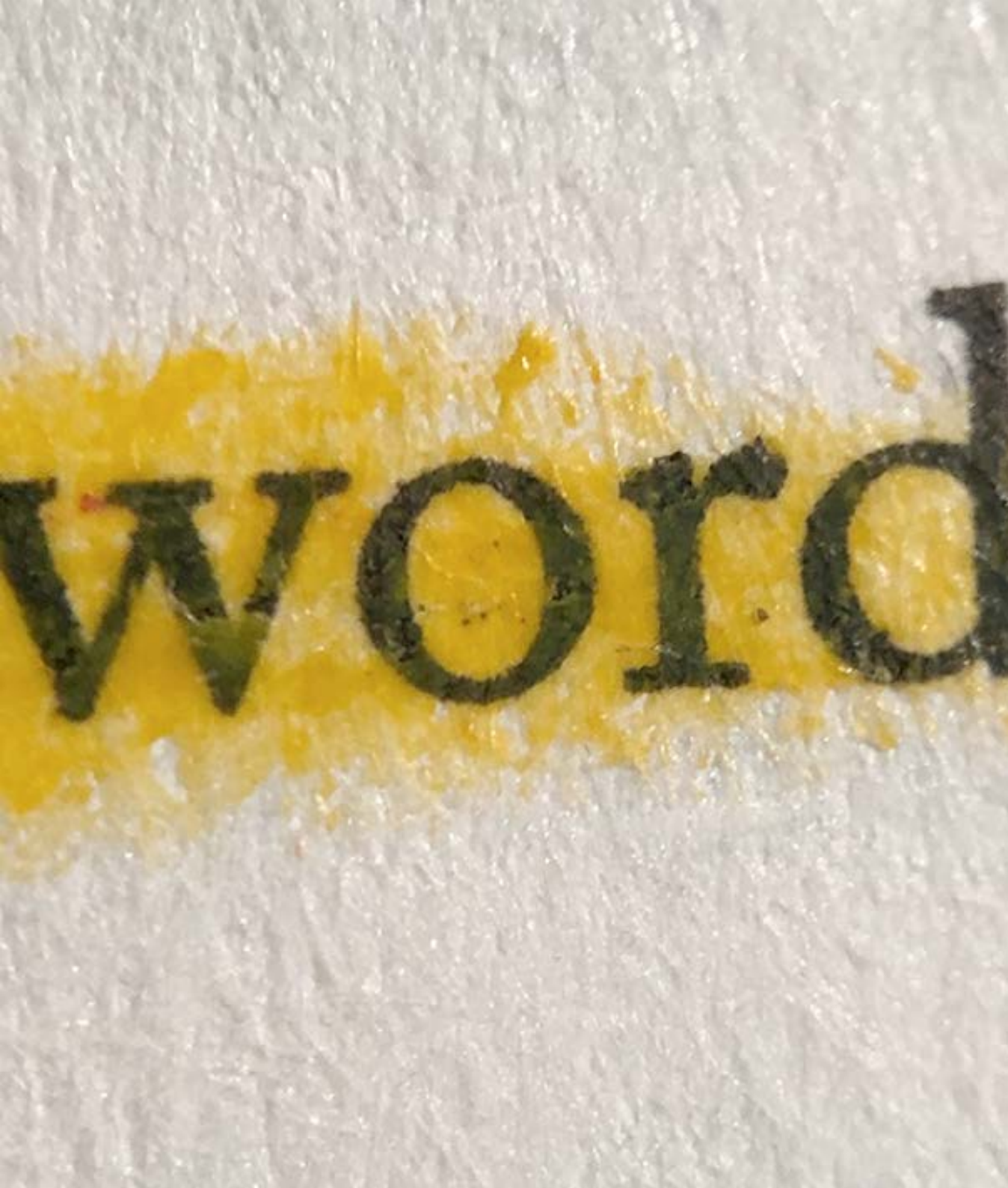
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Jennifer (Eisenhauer) Richardson is an Associate Professor in the Arts Administration, Education, and Policy Department at The Ohio State University. Her research, which is situated at the intersections of critical disability studies, Mad studies, arts methodologies, and art education, engages questions surrounding the practices of disabled, Mad, and neurodiverse artists and writers and the historical and contemporary discourses and ideologies that frame the ways in which their creative work is understood and approached in art education. Her research has been published in journals and books including *Studies in Art Education*, *Visual Arts Research*, *Art Education*, *The Journal of Literary and Cultural Disability Studies*, *Disability Studies Quarterly*, *Journal of Cultural Research in Art Education*, *Contemporary Art and Culture in Disability Studies* (Wexler and Derby, Eds.), *M/othering and a Bodied Curriculum* (Springgay and Freedman, Eds.) and *All about the Girl: Power, Culture, and Identity* (Harris, Ed.) among others. Her prose and poetry have been published in *Rogue Agent*, *Wordgathering*, *Connotations Press*, *DSQ*, and *South Loop Review*.

Abstract

In this visual essay, I begin with a short piece of creative writing through which to first reflect upon discussions within disability studies about the construction of Mad and neurodiverse subjects and subjects with mental disabilities as not being rhetorical, and subsequently non-human (Price, 2011; Prendergast, 2001; Yergeau, 2018). I explore the importance of first-person representations of mental disability for art education as integral for the critical investigation of the social, cultural, and political ramifications of sanism and ableism as they intersect with other forms of oppression. I consider found poetics, not simply as a form of writing, but as a theoretical engagement with the ways in which I have been previously storied in social, cultural and psychiatric discourses.

Keywords: mental disability, mental illness, art education, rhetoric, Mad studies, disability studies



In an isolated room in the psychiatric section of the emergency room, the gurney beneath my body is hard and uncomfortable. Two disgruntled men, a police officer and medical technician, sit outside the door serving as guards and mumble about “these patients” who I know they see most definitely as Other than themselves, as Outsiders.

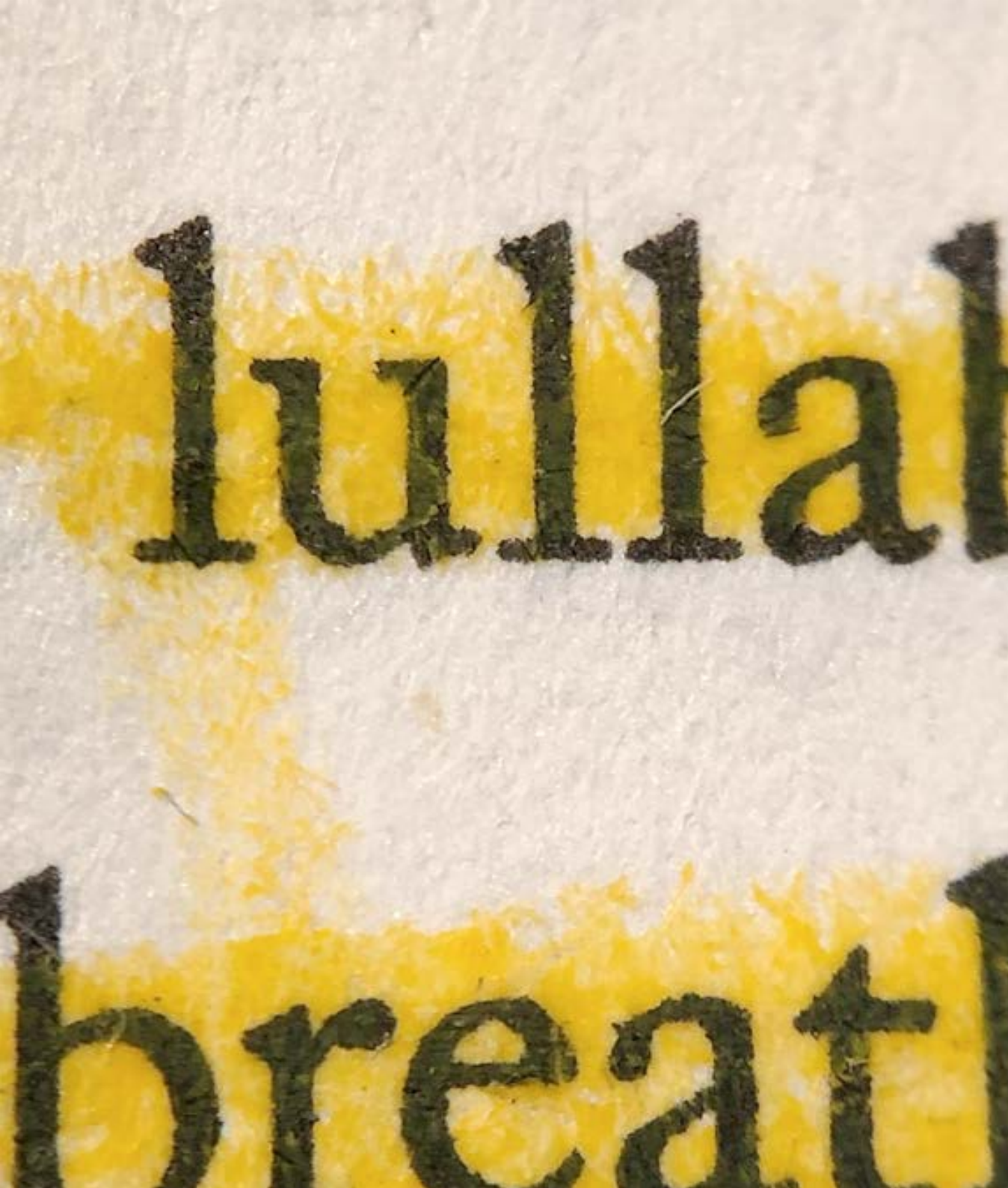
I say that I want to write and the hospital technician gives me a recycled piece of paper and a yellow crayon. So, I lie back down and grab my copy of Terry Tempest Williams’ (2011) book *When Women Were Birds: Fifty-Four Variations of Voice*, a book I asked my husband to bring me. I take that yellow crayon and highlight words to create a found poem.

The first voice

*my mother
womb from
world*

*before the umbilicus
she cradled me*

*a lullaby
breathing.*



The psychiatric emergency room is a separate, but not equal space in which people labeled “psychiatric patients” become positioned as both not being rhetorical and non-human. Within a discourse that works from a presumption of what is in the “best interest” of a person, framed through a biomedical approach, experiences of exclusion, dehumanization, marginalization, and trauma are often perpetuated. One experience of violence is to know that you have lost all power to be heard and that ultimately you are presumed to not even be speaking. When a woman with a mental disability is handed a yellow crayon with which to write, an assumption is made that both a woman and a person with a mental disability has nothing to say. As Margaret Price (2011) writes:

We speak from positions that are assumed to be subhuman, even non-human; and therefore, when we do speak, our words go unheeded.... In concrete terms, this means that persons with mental disabilities are presumed to not be competent, nor understandable, nor valuable, nor whole. We are placed in institutions, medicated, lobotomized, shocked, or simply left to survive without homes. The failure to make sense, as measured against and by those with “normal” minds means a loss of personhood. (p. 26)

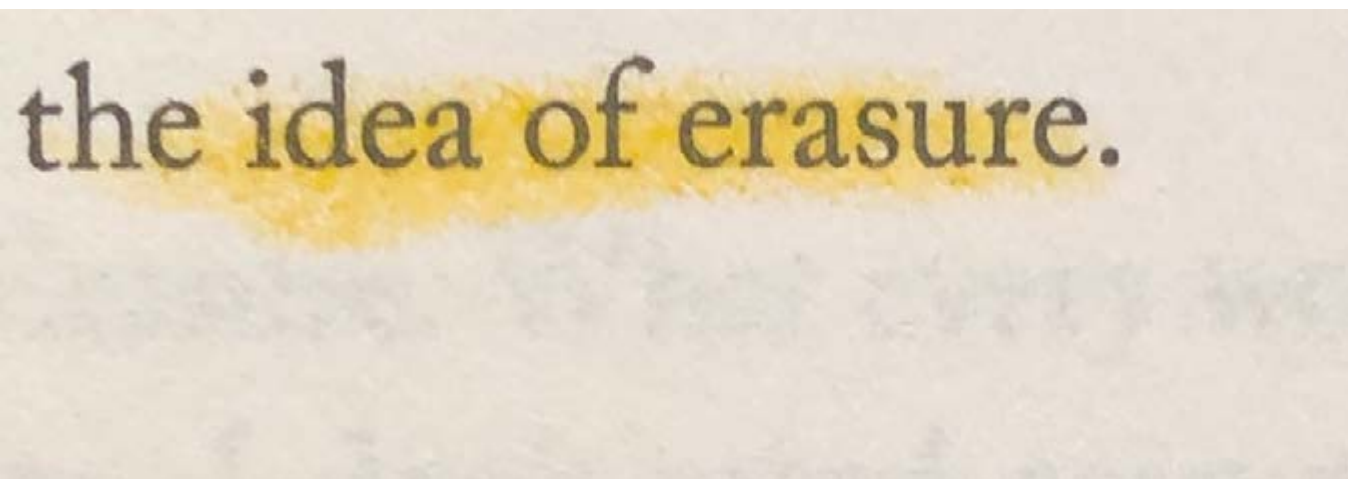
As Melanie Yergeau (2018) critiques in relationship to autism, a designation of not being rhetorical results in being defined as not human. Her argument can be applied to the experience of mental disability.

- One must be human in order to be rhetorical.
- Autistic people are not rhetorical.
- Autistic people are not human. (p. 11)



As a woman, artist, writer, professor, educator, and a person with a mental disability, I wonder if I am writing with a yellow crayon in the field of art education. To identify as a person with a mental disability or as Mad is in a sense to lose one's position as rhetorical, to have one's attempts to call into question sanist¹ practices within art historical and educational practices marginalized as "personal" problems rather than to have sanism recognized as a cultural and social issue that has consequences for everyone. In regard to artists and writers who identify as Mad, psychiatric survivors, as people with mental disabilities, and/or as service-users, there remains a struggle to remove the stigmatizing bright blue hospital gown of psychiatric discourse. It becomes difficult to situate not only myself, but Mad cultures more generally not on the periphery in an isolated ward at the edge of the hospital and the field of art education, but as an integral part of discussions of equity and diversity. Tobin Siebers (2008) wrote, "Closeting involves things not merely concealed but difficult to disclose—the inability to disclose is, in fact, one of the constitutive markers of oppression" (p. 97). However, even in speaking to one's experience, artists and writers with mental disabilities continue to experience the oppression of being positioned as not being rhetorical. Extending Catherine Prendergast's (2001) question, "Does some kind of al/chemical transformation need to occur before the mentally ill can be heard? And in whom does it need to take place?" (p. 203), Price (2011) asks: "What transformation *would* need to occur before those who pursue academic discourse can be 'heard' (which I take to mean 'respected'), not *in spite of* our mental disabilities but *with* and *through* them?" (p. 8).

¹Sanism refers to types of discrimination and oppression of people who are either diagnosed with "mental illnesses" or perceived to have mental differences or experiences of mental distress.



A yellow crayon would seem to be one of the most useless crayons with which to write. When I was handed a yellow crayon, I did not view it as a sign of “respect,” but rather as laden with assumptions that I was too dangerous to yield a pen or pencil, that I was a child, that I couldn’t be trusted to communicate, and that I didn’t have anything to say anyway. However, I deployed the crayon as a highlighter and approached the task of writing through found poetry. I was not aiming to demonstrate that I had the capacity to write nor that I was “competent.” I wanted to write about what I was experiencing and crayons are not generally useful for writing prose. Therefore, it became more about how I *could* use a yellow crayon as a creative tool. Found poetry, as a collage process, is a practice based on the simultaneous deployment of emphasis and erasure. Typically, an author writing found poetry only uses words in the existing text. Found poetry is a process that recycles parts of an existing text, through a decision-making process that doesn’t *dismiss* a prior text, write a completely new text, but converses with a prior text to produce poetic form. The resulting poem was not really an account of the emergency room. However, I do briefly characterize the emergency room in the prose above to provide some context for writing the poem. Rather, the poem was an engagement with writing through the experiences of my bodymind, while subjected to psychiatric incarceration.

The social and cultural delineation of the mental institution and the academic institution is emblematic of a particular construction of rationality presumed to be inherent to the academic institution and an irrationality presumed to be inherent to the mental institution (Price, 2011). However, even within both

rational and irrational spaces the intersections of gender, race, socioeconomic status, sexuality, religion, culture, and other identities further impact constructions of rationality and irrationality, as well as participation in academic institutions. Likewise, the intersections of gender, race, socioeconomic status, sexuality, religion, and culture with mental disability further marginalize and dehumanize individuals and limit access, including access to health care. Therefore, to consider the potential of those with mental disabilities, as Price (2011) suggests, "to be 'heard'... not *in spite of* our mental disabilities but *with* and *through* them" (p. 8), it becomes important to consider how the intersectionality of mental disability identities results in different social and cultural experiences of dehumanization and non-rhetoricity (Prendergast, 2001) themselves.

In art education, it is important to consider and challenge the ways in which we approach students with assumptions like those who hand out a yellow crayon, investigate barriers that impede the participation of researchers and students in university settings, and reflect on what narratives pertaining to mental disability experiences are shared and missing. Some individuals never have the opportunity to become educators, university students, artists, and/or writers because of systemic barriers, biases, and discrimination that prevent their full participation. Likewise, the inclusion of artists with disabilities in curriculum often remains either a blank page, by which I mean not even included, typed as a footnote, relegated to a "special" chapter or an entirely different book, or only included within a particular narrative arc. These texts in art education can result from positioning disability within a medical model, through a limiting storyline, and from the intersections of ableism and sanism with other systems of oppression. All of these issues impact how we prepare future teachers. We must ask ourselves, as a field, if we have yet to view disability as integral to discussions of marginalization, equity, and diversity.

The word "voice" is written in a bold, black, sans-serif font. It is positioned in the lower half of the image. Behind the word, there is a horizontal, irregular smudge of yellow crayon or paint, which is slightly wider than the word itself. The background is a plain, off-white surface with a subtle texture.

Terry Tempest Williams' (2011) book, which I responded to with my found poem, is her own response to finding that all of the journals her mother bequeathed to her after her mother's death from cancer were blank. Throughout Williams' text, she returns to the sentence "My mother's journals are....", each time completing the statement differently. At one point in the text she restates these sentences fifty-four times, line after line, complicating any ability to arrive at one conclusion, adding further depth to her meditative text and perhaps disrupting the temptation to speak for her mother even as she navigates telling her mother's story. In a sense, the blank journal may have been, as Williams suggests, an act of defiance about the expectations that her mother, as a Mormon woman, should keep a journal. However, she still does not arrive at one simple interpretation within her meandering prose.

To reflect upon the ways in which first-person narratives are integral to discussions of marginalization, equity, and diversity, is to begin with the presupposition that Mad and disabled subjects represent an innumerable number of diverse voices characterized by the many ways that they creatively engage and represent experiences of social and cultural disablement. Just as Williams' writing about her mother's blank pages disrupts a singular definition of her mother's experience, how and why artists and writers engage with experiences of marginalization and oppression in their work does not have singular answers. The intersectionality of first-person narratives by Mad and disabled subjects can contribute to discussions of diversity and equity in art education when understood as reflecting numerous voices, forms, and purposes. Following Williams' engagement with her mother's journals, I can only begin by characterizing these creative works in the statement: *First-person narratives are...* knowing that each completion of this sentence will arrive at a different conclusion. These narratives can contribute to art education's continuing engagement with disability beyond medicalization. A consideration of both the process and content of first-person perspectives offers possibilities to highlight issues of social and political exclusion and bring attention to a political and pedagogical rethinking of the intersections of ableism and sanism with other experiences of oppression.

I am left to consider how my use of a yellow crayon and found poetry can inform my ongoing consideration of the interrelationship between the ways I write about my own experiences and the ways in which experiences of mental disability have already been storied in popular, literary, psychiatric, and art historical discourses. There is the temptation to state: *These stories result in x*. This would define this variable with a degree of certainty in how they impact my experiences. However, what if these become the texts with which I am having a conversation? What if I engage these texts through found poetics? Through found poetics, I would not dismiss these prior texts, write a completely new text, but rather converse with these prior texts. I explored this possibility in my conversation with a historical psychiatric text through found poetry (Richardson (Eisenhauer), 2018). Mikko Koivisto (2018) discusses how rap musicians' engagement with stereotypes of race and disability moves "beyond the binary notions of resistance and submission, or rejection and acceptance" (para. 3). Found poetics can become a theoretical approach that results in forms other than poetry, with "poem," "words," taking on other connotations. The "poem" I find, the way I order "words," their selection, articulation, and potential meanings remains contradictory and plural, just as Williams' mother's journals are.... These texts are.... My story can do this.... My story is....

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Archiving spaces: walking, murmuring, and writing with artist Nicole Storm

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Keywords:

artist practice, space, disability, archival performance

Introduction

This visual essay captures my fieldwork experience working with artist Nicole Storm from October 2018 to March 2019 at Creative Growth Art Center in Oakland, California, a contemporary art studio for artists with disabilities. Nicole always carries newspapers and markers when walking through the Creative Growth studio. When talking, she references her belongings and posters, speaks while she writes a line, pauses when a line ends, and then resumes speaking with each new line.

Nicole's mother characterizes her art practice as "archiving" (M. D. Storm, personal communication, December 11, 2018). Nicole collects studio handouts, email printouts, napkins from restaurants, and nametags from studio volunteers. In her artwork, she records her personal memories of travel, furniture in the studio, the people around her, and others who no longer work at Creative Growth. Nicole's practice, however, is more than a formal repository of historical documents and events. Her art exists as a living archive in the Creative Growth studio space. As such, Nicole's art practice constitutes archival performance. The *archive* that Nicole is performing resonates with artist Simone Osthoff's conceptualization of the "archive as artwork" (2009, p.11) that disrupts stable representations of history, and Michel Foucault's theorization of the archive as a "discursive practice" (1969/1972, p.128).

In this essay, I perform archival practice through Nicole's work with photos, videos, and conversations collected during my fieldwork. Interview scripts, videos, images, and writings in this essay constitute an archive that is neither "a complete simulation masking" of Nicole's original experience nor tries to store Nicole's art making experience chronologically (Osthoff, 2009, p.182). Rather, this archive encourages readers to walk, write, and murmur with artist Nicole Storm, who experiences "contingent and dynamic histories in flux, often in real

time, unsystematic and generative” (Osthoff, 2009, p.182). I provide the date and time of each photo about Nicole’s practice taken from my fieldwork and include image descriptions for an audience that uses screen readers (Kleege, 2018). Thus, as a researcher, I too am performing a living archive by exploring the contingent relations between disability

and art in the creative work of Nicole Storm. It is through this writing I also invite you as reader to consider your reading of her work as an archival encounter.



Figure 1. Nicole Storm, Untitled, 2017, Watercolor and ink on paper, 30.25 x 44.25 inches. Copyright 2019 by Creative Growth Art Center

[Image description: The left two thirds of the image are covered with orange, yellow, and pink watercolor overlaid with dark lines. Some lines are short and thin while some lines are thick and long. The right side of image is covered with purple, blue, and light pink watercolor, with lines that have different length.]



Figure 2. Nicole Storm_Feb. 1, 2019_05:29 pm

[Image description: In a gallery space, Nicole stands in front of her artwork, which is figure 1., the painting that has been described previously. She looks at the camera, poses with her hands, right arm folded across her chest and hand curled downward, left arm folded up at the elbow and pointed in line with her right elbow away from her body and her left hand also curled down. She wears a shawl with blue, pink, and purple colors and a nametag with the word "artist" written on it. A piece of paper with green marks and a green pen sit on a gallery ledge that rises a foot above the floor below her painting. Next to Nicole is a blue handbag sitting on the floor.]

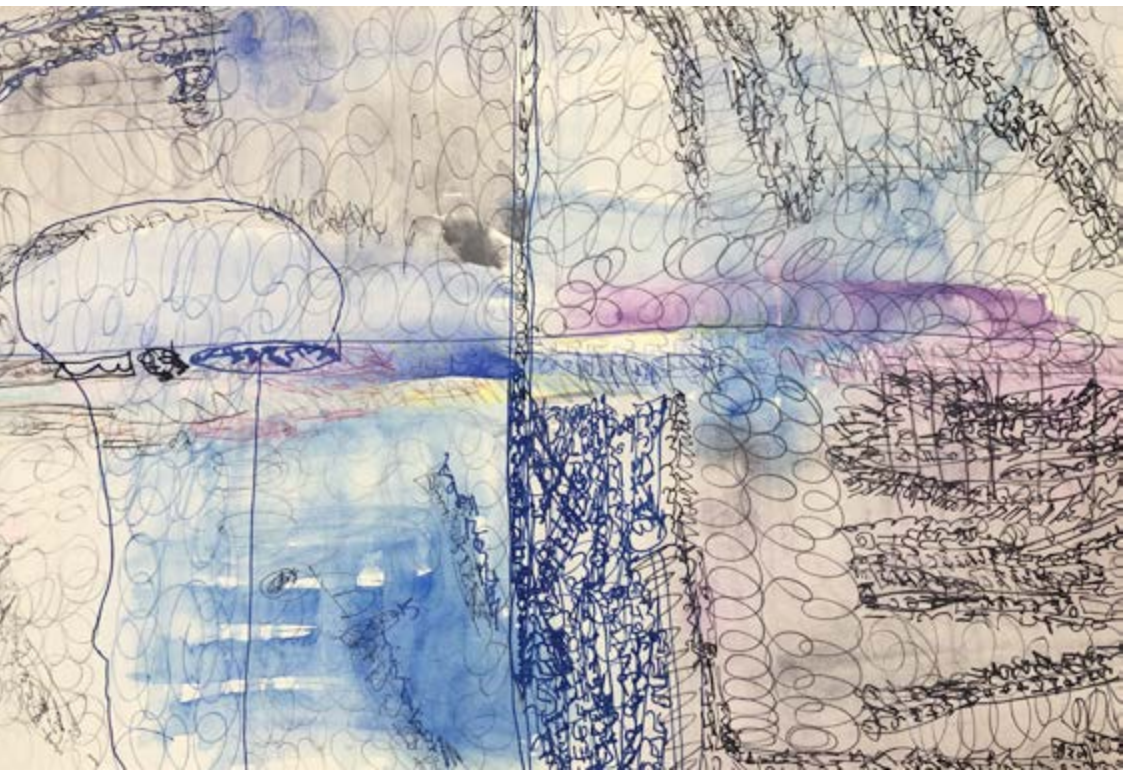
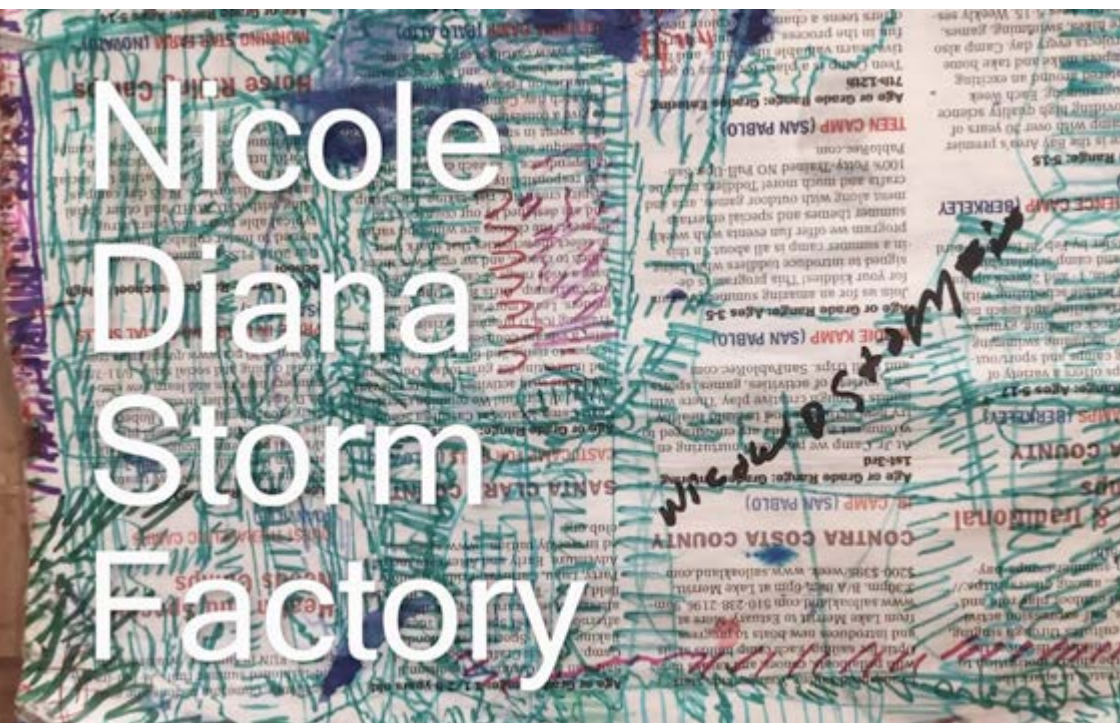


Figure 3. Nicole Storm, Untitled, Watercolor and ink on paper. Photo taken by the author.

[Image description: This rectangular image is divided into four parts by a blue cross. Each quadrant is covered with looping black lines. The right bottom section has layers of blue marks that include waves, letters, cross-hatches, vertical lines, and numbers in the left third of the quadrant and horizontal black markings that include numbers and letters as well as lines. These marking also appear vertically in the right top section in four lined sections coming down from the top vertically and in the left top section's upper left corner. The images are covered by a wash of blue and purple.]



Video 1. Nicole Diane Storm Factory. Link: <https://vimeo.com/314553821>

Nicole Diane Storm shows us her art making process in the studio by wearing a camera. Nicole Storm, the author, and the Digital Media instructor at Creative Growth, Helena Gonzalez, created this video together.

[Video description (Selected scenes): 1) The video Nicole Diane Storm Factory starts with Nicole walking down the stairs towards the X-Frame wood display rack located near the reception desk. She stares at a drawing in the rack that has colorful curved lines and says "wow!" 2) Nicole carries a marker and a stack of newspapers that are heavily marked, walking from the gallery stairs, passing fabric sculptures with faces painted on top of them, the display rack, the reception desk with a staff member sitting next to it, the threshold between the gallery and studio, and looks at the whole studio space. 3) Holding a stack of newspapers in her left hand, Nicole holds an orange marker in her right hand, passing the vending machine on her left and a display rack on her right. Passing by the kitchen area, Nicole arrives in front of the elevator and presses the button, while two artists and one facilitator stand near the elevator. 4) She continues writing on the same newspaper with the orange marker "Ok..." Nicole murmurs while writing and/or drawing on the paper, looking at a pink poster of buildings painted by artist William Scott with the words "who is an outsider?" 4) The scene cuts to the inside of the elevator where Nicole is holding the orange marker and drawing curves on the newspapers. She returns to the first floor. Nicole stops at a rack that has T-shirts with Creative Growth's logo on it. Holding one T-shirt in her left hand, Nicole is writing/drawing with the orange marker on the newspaper, murmuring and looking back and forth between the T-shirt and the newspaper.]



Figure 4. Nicole Storm_Nov. 06, 2018_11:54 am

[Image description: In a sunlit studio space, Nicole holds a rectangular white paperboard with black, blue, and purple marks on it. She looks at the camera and wears a green sweatshirt and a pair of black glasses.]



Figure 5. Nicole Storm_Dec.14, 2018_01:40 pm

[Image description: Nicole sits on the cement floor in front of several wood cabinets and writes on a stack of cardboard. On her left side are rolls of fabric, a multi-layer drawer, a white cabinet with smaller containers in it, a black backpack, two pieces of white paperboard, and a piece of cardboard covered in markings. Two mannequins with dresses stand on the right of Nicole.]



Figure 6. Nicole Storm_Oct. 26 2018_02:19 pm

[Image description: Nicole sits cross-legged on the cement floor leaning back against wood cabinets with a satisfied look. She wears a white T-shirt that says "CAMP HARMON." She is surrounded by a black backpack, a black jacket, three stacks of paper with markings, and three cardboard boxes filled with fabric.]



Figure 7. Nicole Storm_Dec. 11, 2018_11:33 am

[Image description: Using her legs as her desk, Nicole holds a bucket full of markers while writing on a stack of paper. She sits on a black leather couch and wears a Santa hat and a green sweatshirt.]



Figure 8. Nicole Storm_Dec.11, 2018_11:43 am

[Image description: With her back to the camera, Nicole points at a poster with a marker in her hand. The pink poster has images of buildings and reads, "Who is an outsider". Nicole wears a Santa hat and a green sweatshirt, and she holds a piece of cardboard with black lines on it. She is surrounded by two plastic storage boxes, bottles of paints, brushes, and an in-progress painting of buildings.]



Figure 9. Nicole Storm_Dec.11, 2018_11:35 am

[Image description: With her back to the camera, Nicole sits on a wood floor underneath a mobile table, holding a stack of newspaper with markings. A backpack sits behind her. In front of her is a mobile storage cart. She wears a Santa hat and a green sweatshirt.]



Figure 10. Nicole Storm_Dec.11, 20118_11:34 am

[Image description: Nicole crouches on a wood floor, bending underneath a mobile table next to a steel storage cart. Bottles of paints, buckets filled with brushes and markers, a bottle of water, and other supplies cover the table. Next to the table, there is a black leather couch with two pillows and a mobile mannequin beside it.]



Figure 11. Nicole Storm_Dec.11, 2018_11:56 am

[Image description: Nicole walks by in a blur down a hallway with tables on one side and a wall of cubby holes filled with backpacks and other personal items. She carries a blue backpack and holds a black handbag, a stack of newspapers, and a piece of cardboard. She wears a Santa hat, glasses, a green sweatshirt, black pants, and black shoes.]



Figure 12. Nicole Storm_Jan.14, 2019_11:54 am

[Image description: With her back to the camera, Nicole stands by a table and paints on a piece of pink fabric. She wears a rainbow tie dye T-shirt. In front of the table is a clear window with three pieces of paper hanging in it. Outside of the window is an empty street. Buildings can be seen across the street.]

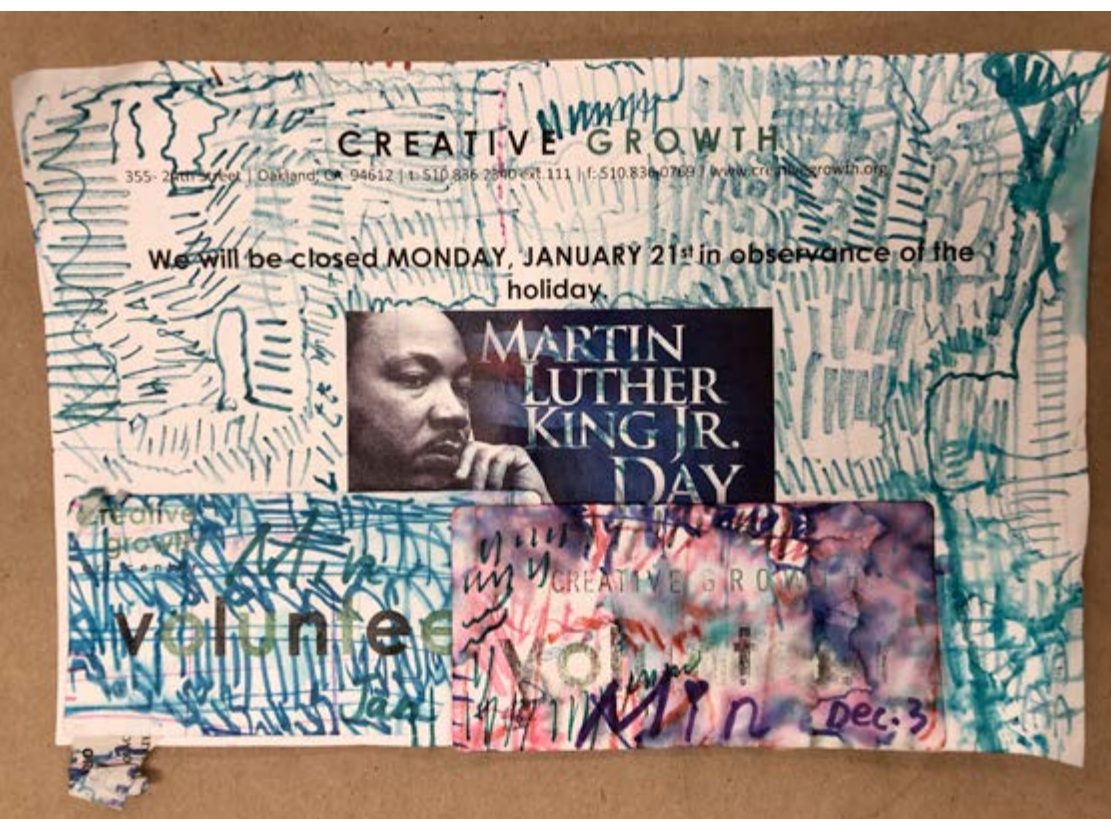


Figure 13. Nicole Storm_Jan. 17, 20119_12:59 am

[Image description: A piece of paper with printed words "We will be closed Monday, January 21th in observance of the holiday." Underneath is Martin Luther King Jr.'s image with "Martin Luther King Jr. Day" written next to it. At the bottom of the paper are two nametags that read "Creative Growth" in small letters with "volunteer" centered in big letters. On the right nametag the name "Min" is handwritten with a heart dotting the "i" and the word "Dec. 3" in small black letters. Part of this text is faded with water-markings and black hatching. The left nametag also has the word "Min" written above "volunteer" and "Jan" written below, but much of this text is covered by blue lines, and hatching covers the rest of the white paper in short vertical and horizontal lines.]



Figure 14. Nicole Storm_Nov. 27 2018_01:45 pm

[Image description: Nicole Storm sits against a brown leather couch below a collage of wall photos and writes on a large paper frame. Poster board, newspapers, bags, and markers cover the couch.]

In Figure 14, in the early afternoon on November 27, 2018, Nicole Storm sat on a long, brown leather couch in a hallway, wearing two layers of sweaters against the cold of the Creative Growth art studio. The back of the couch leaned against a photo-wall next to a square wood table under a bulletin board. Located in between the studio space and the kitchen, the couch is where artists sit during break time or before class begins in the morning. It is a place where one could see the staff or artists pass as they go to the kitchen or to the bathroom. It is also a place where artists would lay down if they felt sick or sleepy. On the opposite side of the couch, there are two bookshelves that contained the Creative Growth's library. The artists often grab a book from the library and sit reading on the couch. Nicole had a different way of using the couch. With her legs stretched out, she sat slouched against the couch. She would draw on a white mat board with a blue Sharpie marker, murmuring to herself, and gesticulating from time to time. Because it was not break-time, most of the artists were working in the studio, and nobody else was using the couch. On the square table, she put a white storage file box containing papers she was currently working with. Her belongings were strewn across the entire length of the couch.

Nicole's belongings included a whiteboard, two brown paper tubes, a piece of brown paper, a poster board with ripped edges leaning against the wall, a backpack with a slice of fabric on which Nicole had rendered a drawing, a soft fabric handbag with a stack of paper in it, a plastic bag with colorful markers in it, a grey sweater with decorative holes on it, a black lunch bag, a piece of yellow paper from the *Days of the Dead* event¹ organized by the Oakland Museum of California with Nicole's writing on it, a red marker on top of the yellow paper, and a short stack of newspapers with Nicole's drawings on them. All of these assembled elements created by Nicole, including the movements of people passing by the hallway, constituted the environment in which she worked.

Nicole's constructed environment constitutes a milieu that resonates with what Derek McCormack (2013) calls an "affective intensity" in relations or "distinctive spatial sensibilities" (p. 58). The hallway space in which she worked was "not so much [a] three-dimensional container for activity but.

. . . shifting configurations of bodies, materials, and ideas taking place with different degrees of affective intensity and duration" (p. 60). It is through the "shifting configurations" in a milieu of the cardboards she carries, the sound of her murmurs, the photos of retired staff on the wall, the memories of being with the staff, and the interactions with artists passing by, that she is affected by the intensities in the space. Yet, for Nicole, this space is not just the setting for her work, it is her work. Nicole is not just working in the hallway space and experiencing its "affective intensity"; she is archiving its "shifting configurations" and using the "bodies, materials, and ideas taking place" to create art (p. 60).

Nicole's spatial archiving practice resonates with artist Simone Osthoff's definition of "archive as artwork" (2009, p. 11), and philosopher Michel Foucault's conceptualization of archives as the "discursive practices" (1969/1972, p. 128) of things and events. Both Osthoff (2009) and Foucault (1969/1972) argue that the archive is more than a "repository of documents" (Osthoff, 2009, p. 11), a mere collection of materials preserved for the future. Nicole's collection of handouts and printouts records memories through drawing, murmuring, and walking in the studio. This practice, however, functions as more than a formal repository of the past. Her purpose is not to affirm, but to reject archival stability as Osthoff contends (2009).

Osthoff (2009) argues that "archive as artwork" (p. 11) rejects history as a stable archive documented chronologically and instead underlines the "temporal and spatial displacement," "ghosts" in our experience (pp. 178–179). She advocates for archival generativity that considers "dimensions of [the] archive that escape...or disrupt representation" and asks questions such as "Whose memories get to be preserved in archives?" (pp. 179–182). In doing so, Osthoff's (2009) characterization of the archive's performativity as artwork forestalls the ghosts of historical accumulation to make way for the "reveries in thoughts" that she argues generate from the uncertain and contingent dimensions of the archive (p.179). Nicole's art

¹Day of the Dead or Día de los Muertos is a multi-day Mexican holiday starting on October 31 where people demonstrate love to family members and friends who have deceased. The Oakland Museum of California has organized community celebrations for the Day of the Dead for two decades. On October 21, 2018, several artists and staff from Creative Growth, including Nicole Storm, joined the celebration. The yellow handout in figure 14 was the event procedure printout distributed to all participants by the Museum on that day.

emerges from these contingent dimensions in archival practice and in doing so, challenges foundational assumptions of disability experience and its relation to art.

Murmuring is a significant sonic dimension of Nicole's archival art practice. Like the sustained, monophonic effect of a drone in music, her murmurings provide a sonorous foundation for the contingent polyphonies of her archival art practice. Examples of her murmurings include the following: "Lisa is not here [anymore]..." (Nicole is referring to Lisa Campbell, another artist at Creative Growth who passed away in early 2018; Nicole is writing on a piece of newspaper at the same moment); "Ok, this is the beginning of a..." (Nicole is pointing at a printout of her brother's email); (A studio volunteer in the hallway shouts out 'Zoe') "Did she just say that name? Ok..." (Nicole, sitting on the floor of textile supplies next to the hallway, is adding several short red lines on a magazine that already has red marks on it).

When murmuring, she always references her belongings, posters, memories, murmurs while she writes a line, pauses when a line ends, and then resumes speaking with each new line. This *murmur-write-pause-resume process* performs a rhythm that resonates with what philosophers Gilles Deleuze and Félix Guattari (1980/1987) refer to as "a communication of milieus" or "coordination between heterogenous of space-times" (p. 313). Deleuze and Guattari (1980/1987) conceptualize rhythm as not occurring in "a homogeneous space-time" that can be measured by chronological or geographical standards. Instead, rhythm is a communication of heterogenous milieus that is always changing and "incommensurable" (p. 313). Nicole's art practice not only highlights the milieu of sound but also underlines the communication between milieus, the sonic milieu (A studio volunteer in the hallway shouts out 'Zoe'), the milieu of memory (Lisa is not here [anymore]), and the milieu of materialized surroundings (an email printout, a magazine, marker).

Nicole murmurs into archival memory different events. She carries objects to different studio spaces and makes temporal marks, layering lines and circles with her *murmur-write-pause-resume process*, on objects on

different days. Put another way, by memorizing, murmuring, walking, and writing, Nicole performs what Deleuze & Guattari refer to as the heterogeneity of space-time (p. 313).

As an archivist artist, Nicole resists archival stabilization. Rather, through archival performance she puts "contingent and dynamic histories in flux, often in real time, unsystematic and generative" (Osthoff, 2009, p. 182). Nicole's mother explains:

In her [Nicole Storm] mind, she is recording events. You noticed there are some letters and some numbers. You and I won't be able to discern them. And I am not sure if she can go back and remember what she is recording at the time. But *in the moment* (emphasized by the speaker), she is recording events and what she is observing or remembering. (M. D. Storm, personal communication, March 7, 2019)

What Nicole's mother suggests is that by observing, taking notes, and drafting her observations, Nicole familiarized with, documented, and archived circumstances and events of her world to memory. Nicole's process of archiving "*in the moment*" resonates with the "very root of [a] statement-event" and "the occurrence of the statement-thing" that emerge from the discursive practice that Foucault defines as archive (1969/1972, pp. 128–129). For Foucault, an archive does not constitute "the library of all libraries" but a dispersive practice that enables statements of things and events to emerge and at the same time, "to undergo...modification" (p. 130). All of Nicole's belongings on the brown couch, her memories with staff, sound emerging from the studio, and people passing by in the hallway allow her to mark and murmur "statements of things and events" occurring around her.

Nicole's mother, as quoted above, also suggests that Nicole might not "go back and remember" the statements that she is making. Rather, Nicole modifies and reenacts the statements in a new way, making another archival performance. In figure 15, Nicole is archiving

her own archival artwork that hangs in the gallery with another piece of paper with a green marker. This performance destabilizes past events. In this way, Nicole's performance disperses the artwork from a fixed representation and modifies it to allow "a multiplicity of statements to emerge" (Foucault, 1969/1972, p. 130). In this archival performance, her art can be seen a "dynamic and generative production tool" (Osthoff, 2009, p. 11). Nicole is performing a living archive in the Creative Growth studio space; but her living archive also extends beyond the physical studio space of Creative Growth with memories of people and outside objects. In other words, she is archiving both physical and contingent spaces.



Figure 15. Nicole Storm_Feb. 27 2018_01:45 pm

[Image description: With her back to the camera, Nicole points at the painting with her right hand (which is her own work) in a gallery space. She holds a green marker and a piece of paper with green marks on it. She wears a blue, pink and purple shawl over a pink turtleneck.]

In the following conversation from my fieldnotes, studio manager Matt Dostal asks Nicole to describe what fascinates her about working at Creative Growth, to which she replies “fascinating together”:

Matt Dostal (Creative Growth Studio Manager): What do you like most about Creative Growth?

Nicole: (She sighs twice). I cannot think of anything.

Matt: You cannot think of anything you like most about Creative Growth?

Nicole: I like... we are fascinating together (At the same time, Nicole is using a marker to write on a piece of newspaper).

Matt: You like what we are together?

Nicole: Fascinating together

Matt: Fascinating together...interesting

Author: Oh

Nicole: Exactly.

Matt: When you come here what makes you most happy?

Nicole: Happy? (Nicole is writing on the same piece of newspaper). It is the natagi makes me happy.

Matt: What makes you happy?

Nicole: A natagi table...

Matt: I don't know what that is.

Nicole: A natagi table is like a buffet table (Nicole is moving her hand to describe the shape of the table).

Matt: A buffet table makes you happy. We don't have a buffet table here. Are you thinking of a hotel or something? What about Creative Growth specifically?

Nicole: Specifically? Hmmm

Author: You can say anything

Nicole: I would say about the furniture...

Matt: The furniture! Interesting.

Author: The furniture, wow.

Nicole: The organization of the offices, the organization of the staff like that. Oh! He is talking about people who are not really here (Nicole is pointing at Matt and continues to write on the piece of newspaper). Lisa is not here...

Matt: So this is one of your favorite topics of conversations...is that the staff who are not here anymore...are very important to Nicole...keep track of people who used to work here (Nicole is still writing on the newspaper while Matt is talking).

Nicole: Exactly. (personal communication, March 7, 2019)

Conclusion

Finally, my experience of Nicole's creative practice is evident in the documentary photographs and video included in this essay. In the above interview, Nicole expressed liking the way everyone and everything “are fascinating together” in Creative Growth Art Center spaces. Rather than liking one particular thing about the spaces, she was enthralled by the Center as a complex of milieus (N. Storm, personal communication, March 7, 2019). These photographic moments show how she assembled materials according to their affective intensities – the way in which Nicole sees space. Each photograph or scene in the video depicts a constructed configuration that when assembled together characterizes the archival performativity of Nicole's art. In doing so, they depict how I experienced the performativity of Nicole's practice: I followed and interacted with Nicole's murmur-write-pause-resume rhythm in different spaces; other times, I was uncertain where she was or where she was moving next. I saw this rhythm in the archival performativity of Nicole's art as layers of circle loops, waves, cross-hatches, vertical lines, numbers, letters, and her walking, murmuring, and gesticulating in different spaces. It is through this rhythm and her contingent relations to memory that Nicole's art rejects archival stability for archival generativity. This essay is generated from my encounter with the archival performativity of Nicole's art and is designed so that the reader may also experience archival generativity. I view this work as functioning as a living archive that allows readers to explore the photographic configurations and rhythmic interactions of Nicole's art through and across spaces.

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Clear margins: a portrait of allies - A dialogue and a map

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Abstract

This writing and art explore the intersections between visible and invisible disability, between cancer and depression, and between a parent and child. As an advocate of inclusive education, the author has begun to trouble their own assumptions concerning practices of Universal Design, which had been based on the adage that “what is necessary for some is good for all.” Tensions between the needs of the few and the good of the many have arisen for the author as an educator, activist, and researcher. Creative non-fiction of personal life experience and artistic play are used here to find analogous ways of approaching these professional tensions. A relational word game is used to unmake a phrenological map, along with assumptions about competence that this diagram represents. By employing dialogue between reality and aspiration, and creating the conditions for serendipity, the author aims to move beyond the binaries of giving and receiving when it comes to care, inclusion, and conflicting needs.

Keywords: cancer, depression, ally, phrenology, inclusion, play

Like many art education scholars (Blandy, 1999; Keifer-Boyd & Kraft, 2003; Wexler, 2019), I am interested in Universal Design as a method of supporting inclusion in art classrooms. My teacher education taught me that Universal Design means providing supports that are “necessary for some, and good for all” (Ontario Ministry of Education, 2013, p. 33). However, I have recently been struck by the question: what if the needs of some are not good for others?

This question has arisen in my teaching practice, equity work, and research. Students come to teachers with many conflicting needs: stimulation versus silence, structure versus flexibility, independence versus support, and so on. In activist discussions, I see that demographic information is a powerful advocacy tool for people of colour, while the visibility required by demographics can endanger the employment and safety of transgender people and the invisibly disabled. Hamraie’s (2017) scholarship relates a productive dialogue between the conflicting needs of wheelchair users and visually impaired people. In the current writing, I take up the microcosm of my relationship with my mother as an entry point to these issues. In particular, I examine the experience of supporting my mother’s recovery from cancer during a relapse of my depression. I investigate how we moved through needs together.

The following section is a creative, non-fictional account of taking care of my mother, through my own need for support. This story is interspersed with italicized quotes from Anne Bishop’s (1994) *Becoming an Ally*. The result is a dialogue between my reality at that time, and my aspirational self. The final section of this essay returns to the question of conflicting needs, by way of a discussion of the artistic portion of this project.

Dialogue Over Lunch

“Oh,” she says, “Do you have a health problem?” This question is embarrassing. The speaker, my mother, is being treated for cancer.

She sounds relieved when I say “Just depression.” Every time this comes up it’s like we’ve never talked about it. A Jedi mind trick: this is not the

dysfunction you are looking for.

There seems to be a cycle of envy between visible and invisible oppressed groups. The visible resent the ability of the invisible to blend in with the mainstream ... the invisible envy [the] visible ... because they can find each other ... (Bishop, 1994, p. 79)

For months I have been under it: “I can’t... *this...* again.” I really think I can’t, but I will. I do. Surviving depression becomes my job. Slow motion decisions. Like filling a bath tub with an eye dropper. I command myself: get dressed. How can that take two hours? Don’t judge; that makes it worse. Remember when these things were automatic. They will be again. Just wait. Talk to your mother.

Try not to look to the oppressed group for emotional support. ... Their energy is needed for their own struggle. (p. 118)

Since the surgery, she can’t raise her arms. She says this is hard on her husband, gets up from the table and moves toward the coffee pot.

“Don’t lift that.” I block her. “I’ll get it.”

“It’s not heavy.” Her smile is a squint. “It’s fine.” But she lets me pour her cup. “I’m fine.” And sits back down.

“If you’re gonna get sick, get cancer in Nova Scotia.” She said that to guests last week without a hint of sarcasm. “Such great care.”

But feeling flashes through pragmatism when the two of us are alone. Deep breaths through detail talk. We scour the medical report. “Incidental” is good; “atypical” is bad. Couldn’t they use another word for “invasive?” We have to look up “hyperplasia,” but we don’t speak the definition: “fast growing.”

Support the process of unlearning oppression with other members of your own group. Do not usurp the role of communicating the experience of the oppression; that one belongs only to members of the oppressed group. (p.118)

Five years ago, a nurse told me not to worry so much about anti-depressants. He stops his own whenever he feels better; it's not a big commitment. In the same office a doctor said that unmanaged withdrawal can cause brain damage. Three years on a waitlist brought me to a psychiatrist who said my sexual orientation is "acting out behaviour." Should I call this care?

More recently a psychologist told me to "accept depression as part of who you are." I protested. I am not a disorder; I have been invaded. She countered: "People who accept their condition don't fall as hard when they relapse." This is the first time I've heard that. It spooks me. Of course a turn is gentler if you expect it. But isn't that an invitation? An open door for the grim return. I want the opposite. Lock it out. I'm a sucker for external cues though. Is that peer-reviewed? Give me statistics, or anything to go on. Only please don't let me be a disorder.

When we work to change these cultural oppressions, many of our tactics are ideological or cultural. They are aimed at ending shame and developing pride in those who have internalized the understanding that they have a lower value than another group.
(p. 82)

Can you have breast cancer without breasts? We'll know in a month. A lab technician will inspect her severed tissue and wait for cells to grow. If the sliced edges are "healthy," we'll know the surgeon got it all. That's called "clear margins." Last time the margins were "close." A millimetre and a half between lump and knife is not enough. That's when she told the doctor to take them both. Afterward, in an attempt to reassure her, a specialist called her cancer "insignificant." My mother's back was board-straight when she said, "then why am I sitting here with no breasts?"

"The worst part is the fear," she tells me now. Chemo possibilities ghost across glassy eyes. I brace myself for the visceral shut down that happens to me when my mother cries, but she doesn't. She closes her eyes and breathes in. "Having my breasts off is not bad." Eyes open, exhale, "Not yet." I don't understand but I squeeze her fingers. My usual resistance to

contact is suspended. I'm drawn in. I put my hand on her shoulder walking by, rest my fingers on her forearm while we talk. I can't stop touching her. *She's still here.*

Last week the nurse told her "you're a candidate for plastic surgery." She doesn't want it. "That won't be me," she says, "It would be like this never happened." Still, she wants to know how it will look when the bandages come off.

"I went to adjust myself," she says, "but I wasn't there. It's not bad." Hands against concave chest. "I'm just not here."

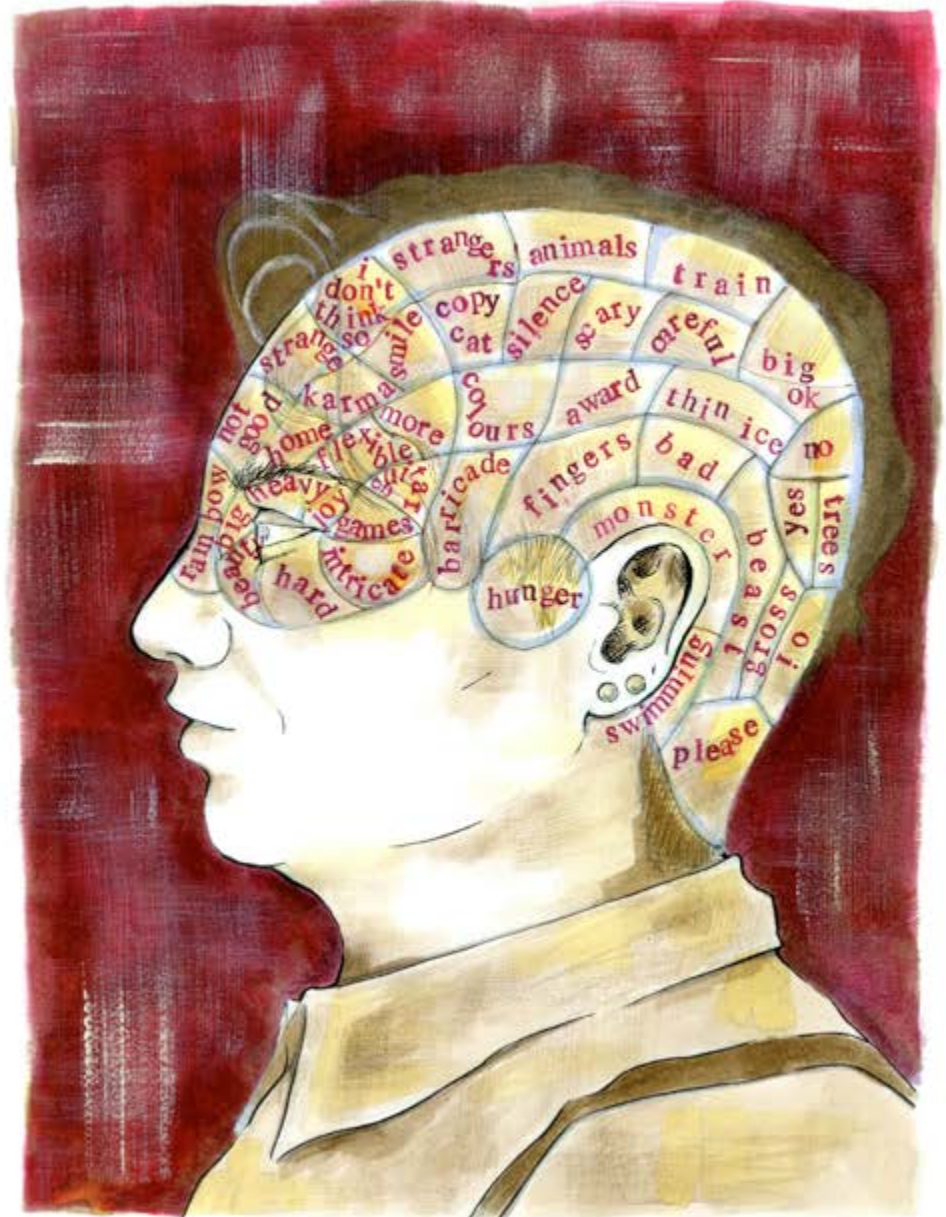
People change. Sometimes the process involves two steps forward, one step back, or even two back, but people do change and heal and grow. People change individually and collectively... (p. 146)

Out of nowhere an image cuts through my awareness. I can't name it. I won't describe it either. This thought-picture tells me both: "I need to feel," and "I need to never feel again." I shut it down. Unseeing my own death is where all my energy goes these days. But this will lift. Eventually depression *lifts*. Do I really have to eat though? Yes. And take positive self-talk like Aspirin. Those thoughts are symptoms. Don't believe them. False alarms make real noises. It'll be ok. Just chew and swallow.

"But how are you?" She flips the conversation back to me. Did I let the *something* cross my face? In any case, it's not my mother's custom to be the centre of things. When she called with the news, she let me talk for twenty minutes before telling me she was tested and that they found "a few, very small cells, that are cancerous."

I say, "I don't want to talk about me right now." Did that sound sharp? Be gentle. She's trying to connect. My smile is her squint. I'm afraid I'll cry if she's kind. Am I capable of connection?

It is important to be a worker in your own liberation struggle, whatever it is. Learn, reflect on, and understand the patterns and effects of oppression, take action with others, take risks...
(p. 117)



Map

At nineteen, my mother took a bus through rural Nova Scotia and sat in front of a talkative woman, who claimed to read the future in the shape of people's heads. The fortune teller put her hands on my mother's scalp and, polite to a fault, my mother allowed this. "You will have six children," the woman said. My mother had two, and later married a father of four. That makes six.

She told me this story while I stayed with her during her cancer recovery. There had been a painful disconnection between us until we spent that time together. But something transcendent occurred at the intersection of my mother's cancer and my depression. Where we both had needs, it was giving to each other that moved us forward. Sharing stories was part of that bonding.

My mother's bus story involves a discredited, nineteenth-century pseudoscience called phrenology that connects the shape of skulls to mental traits. Phrenology attributes particular characteristics to "normal" people, and states that those who lack these qualities are lesser, immoral, or dangerous (Vaught, 1902). Historically, this line of thinking has led to the institutionalization of depressive queers, like me, and the complicity of white people, also like me, in prejudice and land theft, with devastating effects on communities of colour. According to art education and disability scholar Jennifer Eisenhauer (2008), phrenological illustrations are part of a larger cultural desire to visually identify, and stigmatize, people who are mentally ill. I appropriate a phrenological map in the images here, using visual play as resistance.

My mother and I are presented as phrenological diagrams, however we are also specific individuals, intimately engaged with each other. We played a word association game, responding to the name of each phrenological category. Our answers replace the original diagram's labels. Comparing the words in analogous locations on the heads of my mother and myself, leads to found poetry. Between the two images, these words make a *necessary rainbow*, the *joy of hunger* (or perhaps the *hunger of joy*), and

other serendipitous phrases. This work maps a movement away from medicalized stigma, toward an invitation to imagine new common ground.

Returning to the question that began these explorations, when we encounter conflict between the needs of some and the good of others, dialogue and play may bring us to unforeseen new ground.

What could it mean, as educators, to offer support from places of vulnerability, and to ask for assistance from those we perceive as disabled? How can play enable relationships that are not defined by binaries of give and take?

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...not the epitome of normalcy

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Keywords: intersectionality, decentering notions of normativity, Llano Estacado



Figure 1. ...not the epitome of normalcy
Digitally manipulated photograph by Karen Keifer-Boyd (2002)

For five years I lived in Lubbock, Texas, a high desert plain, historically and geographically known as Llano Estacado. While there are plenty of wind and dust storms, there are no indigenous trees and seldom was there a cloud in the sky, let alone rain. A few times a year the rain came as torrential downpours and the sky rained mud. Weather reports used numerous terms for the types of winds in the region and expressed great excitement if a cloud was spotted. The land is a high plateau from which one could watch a sunrise and sunset from the same location without anything blocking the horizon. Hidden from view, until on the edge of gashes in the earth, are deep canyons of red and yellow rock. Driving on the wide flat roads from the hub of the city of Lubbock to find a canyon, seeking a reprieve from flatness, I spotted and photographed a cloud as it appeared to touch the earth. Against the blue sky were long straight rows of white cotton from plants that grew in the semi-arid climate. Along with the flat landscape of orderly rows of cotton plants, are social practices that assume the White abled-bodied hetero-male is the epitome of normalcy in which all others are judged as lesser, as abnormal. There is much more diversity of life than is proclaimed on the surface, like the lifeforms that emerge during the rare downpours through the mud cracks of the playa lakes, a mostly dry lake unique to the Llano Estacado and other semi-arid high plateaus.

The gashes in the land hiding stunningly beautiful canyons, seemed to me to echo the painful stories of people hiding who they are in order to survive. Such stories were shared with me in my home and classroom, while in Lubbock teaching at Texas Tech University, where I offered safe spaces to value the differences of each individual. Their perception of being different from others was often first encountered and enforced on entering school, where white male, able-bodied, heterosexual teachings engulfed them. Three wrote testimonials (one anonymously) published as a chapter that I (Keifer-Boyd, 2003) authored in a book titled, *From Our Voices: Art Educators and Artists Speak Out About Lesbian, Gay, Bisexual, and Transgendered Issues*. One 21-year-old gay White man wrote:

I never interpreted my dislike of high school as relating to a gender or sex problem, it was a matter of being increasingly systematically excluded from things since 4th grade, desiring to be normal and most importantly hating the way young people are treated, as prisoners and not humans, until they undergo enough indoctrination to be sure they will always defer to superiors and not put up much fight. At this point they are allowed to be humans. (Keifer-Boyd, 2003, p. 4)

Students develop feelings of inadequacy when there are no role models who look like them, when histories don't include them, and what is privileged as worthy is impossible to become. The self-descriptors in the testimonies include:

alone, nonexistence, invisible, withdrawn, suicidal, controlled, worthless, miserable, empty shell of a person, catacomb-like state, nonhuman, excluded, something different, desire to be normal, always different, two worlds, solitude, isolation, banished from society, secret lives, lies, and ceased to exist. (Keifer-Boyd, 2003, p. 12)

In plain sight is a double entendre on the high plains of West Texas, in which digital manipulation of my photograph of the landscape situates same-sex partnerships on even plain, visible above ground. Intersectionality is suggested in the use of a gray-scale color palette lit by the non-uniform rays of the sun, which breaks the silence, breaking through the cloud that had at last planted itself asymmetrically on the horizon, decentering notions of normativity. For students with disabilities, students of color, transgendered youth, among other decentered positions, the art classroom can offer a sense of belonging within the environment.

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IMAGINE a place photographed by those who cannot see

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Her actual research deals with collaborative art practices in educational contexts involving a cultural diversity under a socially engaged art perspective. She has been a reviewer of several journals and currently she is part of the Editorial Team of an open journal *Artes plásticas, estética y diseño* published by ULL. Her Ph.D dissertation was focused on the relationships between photography and blindness by designing accessible photography methodologies and later on inclusive initiatives around visual interpretation. The results of all these educational and research experiences have been published in several articles and shared at National and International Conferences.

Keywords: photography, blindness, visual imagery, inclusive pedagogy, time.

Palabras clave: fotografía, ceguera, imaginario visual, pedagogía inclusiva, tiempo.

Introduction

This visual essay is the result of a project entitled An imaginary place for those who see and those who are blind carried out within the Complementary Actions program of the Faculty of Fine Arts in Complutense University of Madrid. This proposal integrates an exhibition and a seminar for Fine Arts students and also open to those people who might be interested in the topic. Our role as organizers of the initiative was to engage participants in a proposal for a collective interpretation of blindness photography based on our exhibition. So, an inclusive project was collaboratively developed by the author and participants in which sighted and blind people work in the photographic creation and interpretation of an imagined place. Based on the experience of Peña (2014c), blind people describe an imagined place through photographs created by themselves. Photography, as Lemagny (1999) points out, connects us with the imaginary, regardless our visual condition. Bavcar (as cited in Mayer-Foulkes, 2005), a well-known blind artist, explains how photography represents traces of what we imagine, and a blind person who imagines is capable of internally representing an external reality. So, arousing the curiosity of the visual world that surrounds us and connecting it with the imaginary that blind participants possess is one of the first goals. In this workshop (Peña, 2012, 2014a, 2014c), we asked the blind participants to imagine a place they travelled. Initially we wanted them to share their memories of those trips and then we would work step by step on each photograph. Their pictures became photographs because we had worked with their memories, and memories were indeed visual internal representations the blind persons had about these places. All the photographs created by each participant were turned into visual narratives evoking exotic

places. All were part of an exhibition of the project *An imaginary place for those who see and those who are blind*.

We started our seminar visiting this exhibition of photographic narratives created by a group of blind people, and it was also our first step towards opening a dialogue about blindness and imagery. Afterwards, sighted participants are offered a comfortable sofa so that they might imagine, as if dreaming, and describe one imagined place portrayed in the photographs. Audio description (AD) becomes another form of visual representation that connects with the imaginary, while providing an inclusive approach to understanding visual creation from blindness. Kleege and Wallin (2015) propose other inclusive uses of AD from a pedagogical approach emphasizing the expressive potentiality of visual description.

While sighted participants of this seminar were describing their places, the author was involved in creating her own narrative through the camera. The length of each description determines how long the camera shutter remains open in each photograph. The author's interest lies in creating connections between time and what is visible through the camera.

In our earlier experience (Peña, 2014b, 2014c), blind people used photography as a visual trace to describe an imagined place, just as Bavcar (as cited in Lemagny, 1999) does. Conversely, in this project, sighted participants use oral description to create a sensorial representation, rather than use only their visual sense. It is intended that all people involved, regardless of their visual condition, are aware of the need for this imaginary as a precondition to creation. Everyone plays an active role as creator giving meaning to the project, while enabling us to become aware of other ways of understanding visual creation from an alternate visuality.

Introducción

Este ensayo visual es el resultado de un Proyecto titulado *Un lugar imaginado desde la ceguera*, realizado en el marco del programa de *Acciones Complementarias* de la Facultad de Bellas Artes de la Universidad Complutense de Madrid. Dicha propuesta integra una exposición y un seminario dirigido a los estudiantes de Bellas Artes, así también abierto a aquellas personas interesadas en el tema. Nuestro papel como organizadora de la iniciativa consistió en generar junto a los participantes una propuesta sobre la interpretación de fotografía desde la ceguera basándonos en la exposición. De este modo, llevamos a cabo una propuesta inclusiva y colaborativa en la que tanto la autora como los participantes se involucraron. En ella los participantes como las personas ciegas trabajaron en la creación fotográfica e interpretación de un lugar imaginado.

A partir de la experiencia de Peña (2014c) personas ciegas narran un lugar imaginado a través de fotografías que ellos y ellas mismas crean. La fotografía como apunta Lemagny (1999) nos vincula con el imaginario que tenemos en nuestro interior, independientemente de nuestra condición visual. Bavcar (citado en Mayer-Foulkes, 2005), como artista ciego reconocido, explica como la fotografía representa la huella de aquello que imaginamos y cuando un ciego imagina es entonces capaz de representar interiormente una realidad externa. Despertamos así en nuestros participantes ciegos su curiosidad hacia el mundo visual desde ese imaginario que poseemos. En aquel taller previo (Peña, 2012, 2014a, 2014c) pedimos a los participantes ciegos que imaginaran un lugar al que habían viajado. Con esos recuerdos queríamos que compartieran los recuerdos sobre aquellos viajes y posteriormente trabajar paso a paso con cada una de las fotografías que crearon. Sus imágenes se convierten en fotografías porque previamente trabajamos en aquellas representaciones internas que las personas ciegas habían imaginado sobre sus lugares favoritos. Todas aquellas fotografías creadas por cada uno de los participantes se transformaron en narrativas visuales que evocaban sus lugares exóticos. Estas narrativas visuales fueron parte de la exposición del

Proyecto *Un lugar imaginado desde la ceguera*.

Comenzamos el seminario visitando la exposición de las narrativas fotográficas realizadas por las personas ciegas, lo cual fue el punto de partida para abrir un diálogo sobre la relación entre imágenes y ceguera. Posteriormente, a los participantes que ven se les brindó un espacio confortable para que así fuesen capaces de imaginar como cuando uno sueña y narrar como sería ese lugar que imaginado retratado en las fotografías. La audio descripción (AD) se convierte en otra forma de representación visual que conecta con ese imaginario que tenemos todos y todas, al tiempo que brinda un planteamiento inclusivo de entender la creación visual desde la ceguera. Kleege y Wallin (2015) proponen otros usos inclusivos de la AD desde un enfoque pedagógico destacando la potencialidad expresiva de la narración en relación con las imágenes. Paralelamente y mientras cada participante describe sus lugares, la autora crea también su propia narrativa a través de la cámara. La duración de cada descripción determina el tiempo que el obturador permanece abierto en cada fotografía. La finalidad que persigue la autora es establecer vínculos entre el concepto de tiempo y lo que visible a través de la cámara fotográfica.

Si en la experiencia anterior (Peña, 2012, 2014b, 2014c) las personas ciegas utilizan la fotografía como huella visual y táctil para narrar un lugar, tal y como Bavcar (citado en Lemagny, 1999) lo hace. En este proyecto, se pretende que aquellas personas que ven, utilicen la descripción oral para crear una representación sensorial inspirada en las fotografías realizadas por las personas ciegas. Todas las personas involucradas, sin importar de su condición visual, son conscientes de la necesidad del imaginario como condición previa a la creación visual. Cualquiera puede adoptar un rol como creador/a aportando significado al proyecto, al tiempo que permite concienciarnos sobre otros modos de comprender la creación visual desde otra visualidad.



Figure 1. The place where blind people photographed each other.



Figure 2. Four blind people posing and photographing in an imaginary place (J.M. Villanueva, G. Moya, J.L. Andrés, M. Monasterio) (from left to right).



Figure 3. Four symbolic pictures of objects evoking those imaginary places (J.M. Villanueva, G. Moya, J.L. Andrés, M. Monasterio) (from left to right).



Figure 4. The place where sight people described being at these imagined places.

01:10

I like Chema's photographs because... He said he set all of the pictures in a cheerful way, so I try to place myself in that position of the images.

I like it because you see something... something interesting in the background. I imagine there are boats and maybe you are lying on the beach seeing the horizon while you see the boats that sail trying to reach the horizon.

I imagine myself lying on the beach, with the sea in front of me, some mountains around, and you may sink your hands in the sand and feel some seashells on your hands.

He talked about the way photos are organized like a waterfall. Imagining myself in the imaginary world of Chema, I would like the water to drag me to the sea, that I feel something pleasant, like melting with the sea.

He uses the word "joy," which led me to imagine all of this.



Figure 5. One minute and ten seconds of an interpretation of a photograph (E. Sala) taken by a blind people (J. M. Villanueva).

02:13

The truth is that Gabriel has surprised me by the way in which the seashell took him to such a joyful world. Surprisingly I see again the picture and I agree with him.

Always, when we observe a seashell we have the feeling that it expresses "beauty." Although you have seen one in winter, it takes you to the warm weather of spring or summer. When I was living in Greece I saw a lot of shells there, I keep them very much in my mind. I also think of their sound or, more precisely, the music they have. You may have one at home, they look totally silent, but in reality they would take you to their music. I agree with Gabriel because we are in two different worlds, I have seen them, but he doesn't, although both of us have listened to the sound they make.

Eventually, he says, he wanted to say goodbye to everything. But, you still have the feeling of its music. It's a story where you can't say goodbye even if you want to because it goes on. The seashell is the symbol of peace and joy.

Gabriel took me into a beautiful world.

Thank you Gabriel.



Figure 6. Two minutes and thirteen seconds of an interpretation of a photograph (D. Londo) taken by a blind people (G. Moya).

02:14

The place José Luis leads me to is a very warm place. He explains it with an eloquent image in which he raises his head to see what the weather is like, whether the sun is on his face or not. Then he talked about a garden of cactus and... it must be a fairly dry place.

I loved the way this lizard reaches to the orange lava. There are two sequential pictures that led me to think about the experiments of the avant-garde cinema. It's incredible how this lizard, step by step, gets into the tongue of fire, reinforcing the idea of being at an arid place, full of lava and stone.

At the end he has another portrait with his eyes closed and he says "all good things come to an end" as a premonition that augurs that the end of something pleasant is coming. It has caught my attention quite a lot.

And this is all I can tell about it.



Figure 7. Two minutes and fourteen seconds of an interpretation of photographs (M. J. Ollero) taken by a blind people (J. L. Andrés).

01:46

I'm listening to Monica's song. It's a very soft song, it's very quiet but not quiet-sad, it's quiet-happy. It has like a Habanera rhythm, but a Habanera that instead of pigeons, like all habaneras, has seagulls. Then I imagine it as messenger gulls flying from one place to another. I'm listening to this song and it's flowing like a calm sea, like if you were in a very peaceful ocean, with the waves rocking with the wind in a sunset that's already stopping breathing and melting.

It sounds like a mantra that does mmmmmm, but a mantra that makes good to our soul, makes good to our heart, it makes you relax to your mind and with an almost hypnotic voice that leaves you ... lets you go.

Suddenly, I see on the horizon a very warm light as a dream that is coming. Then I close my eyes and your favorite song is playing inside the music box.



Figure 8. One minute and forty-six seconds of an interpretation of a photograph (P. Cadavid) taken by a blind people (M. Monasterio).

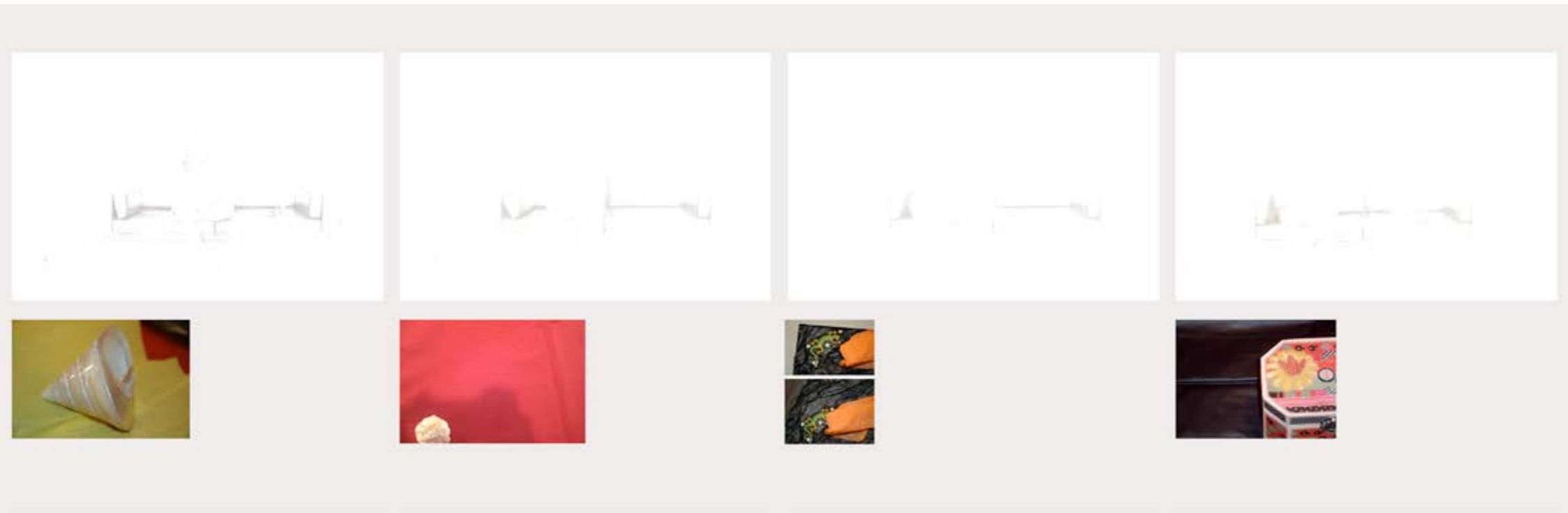


Figure 9. Four sighted people have been photographed during the time spent describing their imaginary place (N. Peña), and below them four visual cites of their pictures are placed. (M.J. Ollero, D. Londo, E. Sala, P. Cadavid).

Conclusions

This project has turned out to be more expansive as it opened up new discourses among all participants. It is worth mentioning that once the narrations by sighted people were done, we decided to share them with the four blind people who made the photographs. During this session they were amazed by the evocative power of their own photographs. Knowing that they communicated ideas through pictures was exciting for them, thus discovering the powerful connection of photography. As one of the blind participants said "Just knowing that I am able to photograph, it looks small but in reality it is a huge step. I never thought I would take a picture again."

Our approach is not to talk about blindness as a disability or as an exotic topic. By contrast, blindness is posed as a new visuality that, according to Peña (2014a), offers other ways of understanding photography from a blind perception that enriches our way of creating images. Nigenda (as cited in Acosta, 2006) suggests that all photographers experience taking photographs without sight; it provides an aesthetic quality and other sensations that might enrich their perspective of photography. Michalko (2010) states "blindness reflects sight and it shows sight to itself, something it cannot see without blindness" (Cool Blindness Time section, para.4). This quote illustrates how blindness is actually another way of perceiving the world as unique and diverse, and may enrich our way of perceiving and understanding visuality. The ability to imagine is inherently human: "if we were not able to imagine first, we would not be able to see" (Lemagny, 1999, p. 52).

This approach requires undoing prejudices about the abilities of blind people for both sighted and blind people. The participation of both blind and sighted participants has been crucial in this project, positioning blind people in an active role as creators, and sighted participants as active spectators creating their own narratives. We must overcome the idea of blindness as an object of curiosity that is analyzed and observed (Thompsonson & Warne, 2018).

To conclude, this project is a single step toward what we might consider socially engaged art (SEA) in which "art" is a vehicle to transform and generate changes that promote a more inclusive society. "SEA, as it manifested today, continues in the spirit of these practices but often expands the depth of the social relationship, at times promoting ideas such as empowerment, criticality, and sustainability among participants" (Helguera, 2011, p. 12).

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Seeing and seeing through: negotiating the intersection of feminism and disability

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Alexandra Allen is a Post-Doctoral Scholar of Art Education in the School of Visual Arts at the Pennsylvania State University. With a PhD in Art Education from Florida State University, her research focuses primarily on individuals with disabilities and how they develop and renegotiate their own disability identity. Using theories from disability studies, Alexandra continues to generate artwork that addresses issues of ableism in an effort to challenge the stigmatized notion of mental health disorders within a normative society. In her most recent work as a practicing artist, Alexandra's creations are largely in abstract form, combining various methods including watercolor and ink to encapsulate her own disability experience as she explores the sociocultural factors that perpetuate performative able-bodiedness. With a background in teaching individuals with disabilities, she aims to integrate disability awareness into her pedagogical practices, particularly for preservice students. Alexandra is currently a member of the conference executive board for Disability Studies in Art Education and has contributed publications on the intersection of Disability Studies and Art Education in the *Journal of Curriculum Theorizing* and the *International Journal of Education through art*.

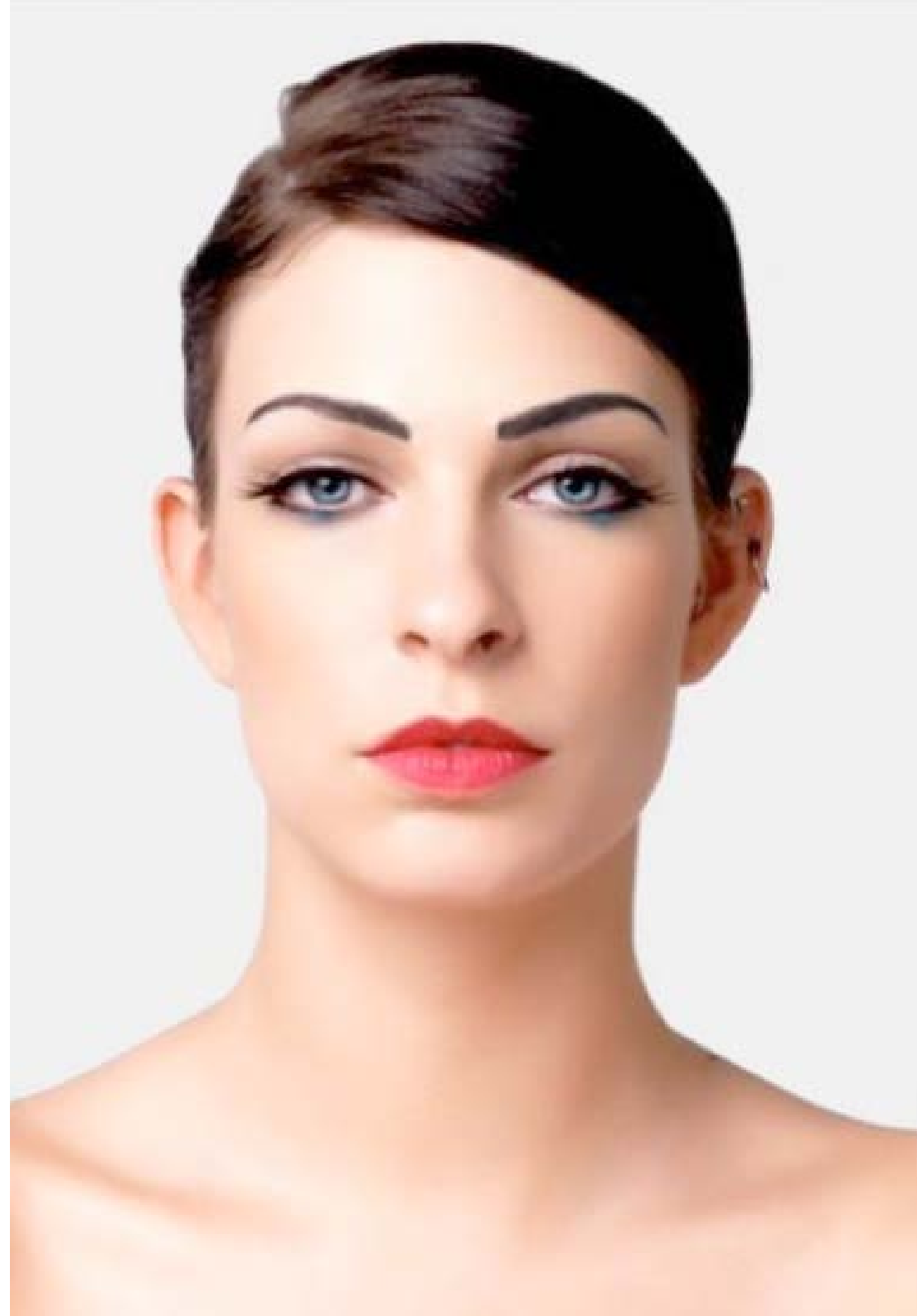
Abstract

This visual essay merges together the arts-based practice of narrative autobiography and the use of visual images from a three-dimensional piece that is intended to represent the intersectionality of being a woman with invisible disabilities. Through the use of first-person narratives that support my understanding of the renegotiation of my own identity, I investigate how one's perception of self can be shaped by her perception of others. In this essay, I examine the dichotomy and the reconciliation of the gaze and the stare, particularly in relation to how these two forms of looking can be characterized once discursive and corporeal forms of performativity have been established.

Keywords: intersectionality, disability studies, art education, performativity, feminism

The gaze and the stare are two practices of looking, intended as a method of social oppression, which objectify the individual being observed. Garland-Thomson (1997) differentiates between the stare and the gaze by implying that the gaze sexualizes the female form, whereby the stare is a way of looking at the disabled as a “grotesque spectacle” (p. 285). Furthermore, she addresses the role that the gaze and the stare have on an individual’s social status, noting “feminization prompts the gaze, while disability prompts the stare. Feminization alterations increase a woman’s cultural capital, while disabilities reduce it” (p. 287). The intersection of the gaze and the stare is relevant to my personal experiences as a woman with disabilities because it has, in a way, produced a unique understanding of self.

As a young woman I became accustomed to the male gaze. In many ways, I learned to use the sexualized predisposition of the gaze to my advantage. As soon as I was deemed an adult by most customary standards, I left my home to pursue a career in modeling. I became desensitized to objectification and I began to accept this type of scrutiny as normal. As time went on, I started to reevaluate my perception of reality and the expectations that I was holding for myself. I was getting older and it was starting to show in the way I looked in photos and the way I was looked at by the opposite sex. I wasn’t as thin or as innocent as I once was. I started to question not only my worth as a person, but also why I had to adhere to a certain standard that felt both arbitrary and unrealistic. Eventually I hung up my tape measurer and moved on to academia where I felt I had some control over my own success.



I have always found purpose in being productive, so it seemed natural to bury myself in schoolwork and to continue to give myself a task-oriented direction. The one thing I didn't consider was how such an intense workload would affect my mental health. As I was racing through my combined undergraduate and graduate degrees, I came upon a massive roadblock. I couldn't understand what was happening to me, but I was having trouble focusing, I was tired all the time, and eventually I started having panic attacks so frequently that I couldn't attend many of my classes. I had come to a screeching halt and it seemed as though I didn't have the control to start back up again. Several medical exams and hundreds of dollars later, I learned that these issues were psychosomatic; physically I was perfectly healthy. These symptoms that I was experiencing were tied directly to mental health disorders that I didn't know I had. I sensed at an early age that what I thought and the way I felt might not be considered "normal," but my introspection and subsequent questioning was always met with some patronizing remark about how I was just going through a "phase." For many years I ignored my disabilities and the tapping on the window of my mind that begged for recognition. The tapping eventually turned into hammering, and after being overlooked for so long, my disabilities began presenting themselves in ways that I could not ignore.



Over the course of three years, I was diagnosed with seven mental health disorders. Some of them made sense—like depression and anxiety, while others—like agoraphobia with concomitant panic disorders, did not. All at once I had to reexamine my own identity among these new diagnoses that I had not anticipated. As the recognition of these new facets of my identity began to sink in, I started to notice a shift in the way that I perceived the world around me. Simultaneously, I also started to notice a shift in the way I believed I was being perceived by others. What I once discerned as the gaze slowly began to shift into something more menacing; I was no longer being looked at; I was being looked through. It felt as though the eyes that observed me were no longer objectifying, but rather inspecting—probing into my mind to examine every anxiety and every fear that had been generated since the moment I sensed a set of eyes upon me. Through obtaining self-awareness over time, I began to recognize how the male gaze had gradually become the stare—leading me to feel like an enfreaked spectacle, constantly being watched. It was in this moment that I recognized how dehumanizing both the gaze and the stare truly were.

There is a nuanced complexity to having numerous intersectional, transitioning identities, specifically in relation to how they are performed. Gloria Anzaldúa (1987) discusses her experiences of intersecting social identities, using the term borderlands to describe existing on the margins of these different identities in a place of hybridity where one cannot be one or the other, but instead a mixture of each. The theory of borderlands is important as a woman with disabilities, as I exist on the social borders of being a “spectacle” in one form or the other, depending on the ways in which I am perceived. During this introspective investigation, I created an artwork that I believe represents these borderlands of intersectionality: a three-dimensional piece that establishes its place within its own shifting environmental context. This artwork, in conjunction with my written narratives, serve as a method of critical arts-based research that challenges the hegemonic tendency to fetishize that which is seen as sexual or deviant. Finley (2011) states, “unique within the broader genre of arts-based research are critical researchers’ goals of using the arts in a project of social and political

resistance to achieve social justice” (p. 561). It is my intention for this research to contribute to the discourses of intersectional identities as a means of political resistance, particularly those which are subject to regulatory regimes inherent in a patriarchal, normative society. For this project, I chose to weld together fragments of mirror and glass to show the state of unrest that occurs when one perceives the gaze and the stare both simultaneously and alternately. This is what I believe it means to be both seen and seen through as a woman with disabilities.



My inadvertent acts of femininity and my subsequent acts of passing had defined most of my life. Actions, however, only constitute the corporeal aspects of performativity. The discursive facets of performativity, however, reveal how minority groups can become disenfranchised solely through language (Kuppers, 2013). Judith Butler (1990) states "language gains the power to create 'the socially real' through locutionary acts of speaking subjects" (p. 156). This concept is directly related to my own diagnoses, whereby I did not identify as disabled until a specific speech act deemed that I was. How peculiar, then, that I had performed in the interest of the gaze, only to recognize (and later resent) the stare once I had accepted the locutionary acts of my own diagnoses. Writing about my experience with the gaze has led me to understand how discursive methods of performativity play a vital role in the ways in which I perceive myself and others around me.

The combination of both visual and word-based research allows for the exploration of the multiplicity and complexity of the human experience (Guillemin, 2004). Karen Scott-Hoy and Carolyn Ellis (2008) state, "many arts-based researchers combine their art with story. The art part of the project, which creates moods and images, combines with writing, which is better at directing emotion" (p. 12). Through the recognition of having disabilities via the act of being diagnosed, I began to internalize similar forms of looking in different ways; and due to issues of ableism, such as the stigma attached to mental health disorders, I began to perceive the negative connotations of the "stare." It wasn't until I started constructing the three-dimensional sculpture that accompanies this narrative that I was able to reinterpret these internalizations as a product of normative expectations that are built upon a medicalized understanding of disability. Although this piece was initially intended to show how the gaze and the stare differ, it still stands as one unified structure. This piece, therefore, represents how the act of the gaze and the stare need not have distinct agendas because both have the same outcome: looking at and looking through.

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An interview with visual artist and body positivity activist viola thiele on visible hidden disabilities

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Nina Stuhldreher (Vienna/ Berlin/ Internet) is a perpetually re-emerging visual artist, university lecturer and alternative realities activist with multiple incompatibilities. She has exhibited and lectured internationally and is currently - while trying to exorcise academic discourses from her own brain – aiming to help establish a debate on neurodiversity in the art field. Following her interest in the entanglement of normativity and surveillance, she has been lecturing on disability studies, internet activism and cognitive disobedience from a feminist perspective at the University of Art and Design in Linz (Austria).

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Abstract

As part of my research into non-normative bodyminds as epistemological tools, I have conducted interviews with artists with hidden disabilities. "Fatness" is in plain sight but not (yet) fully canonized as disability, thus remaining invisible. Visual artist and activist Viola Thiele shared her experiences and strategies in regard to fat shaming on body positivity with me.

Keywords: hidden disabilities, fat positivity, shame, gender roles, artistic genius, bodymind, ableist gaze

Viola Thiele is a classic Berlin-type artist: well-read, expert in both contemporary theoretical debates and fashion trends, with a wide range of skills from graphic design to music production, and with a multilateral versatility that allows her to speak comfortably in both high and subcultural art. She holds an MA in “Art in Context” from University of the Arts Berlin, works as political educator about German Nazi history with young students, and has an artistic career that reaches from gigs in off-spaces to performances at prestigious institutions like Fondation Cartier Paris and the Venice Biennale. She is part of an artist’s community where anti-discrimination politics, feminist theory, and a certain criticality towards normativity, are understood as essential elements and preconditions for a contemporary approach to art production. And yet, even in that environment, one important aspect in Viola’s life has so far been overlooked as a social problem and categorized as a merely personal one, or even regarded as her own fault: her body size. In the context of my research into non-normative bodyminds as potential epistemological tools that can help generate more universally valid new perspectives, I became interested in the social effects of invisible disabilities that especially artists experience. I decided to interview Viola in regard to this topic. While in plain sight, “fatness” is not (yet) fully canonized as a disability and, as such, remains invisible. Approaching the experiences of someone with a non-normative body size with the same set of questions as those I chose for artists with “classic” hidden disabilities, seemed to me to be the appropriate method.

Our conversation was even more productive than expected. Viola’s thoughtful observations about her own and other people’s ways of dealing with her appearance bear the opportunity to make the skinnier-bodied rest of the world realize how canonized—or brainwashed—we all are in relation to our concept of what is a “normal” body size. Applying this perception onto more general aesthetic theories and extending the deconstruction of the socio-optical filter trained into us from its view onto body norms to that onto all visual forms, the ability to see the world with the eyes of a “fat person” could even be a game changer in relation to the goût that has been perpetuated for centuries

within the (white, Western) field of high art. This potential change of perspectives shows the productively disruptive power that disability studies can have, and should actually come with a trigger warning for art educators—as it could result in no less than causing the existing system of academy entrance exams to tumble, which nowadays are mostly not testing craftsman skills, but are rather a selection method for incoming young artistic positions expected to match the dominant taste and thus guarantee the continuity of what one might call a certain *ableist gaze*. The following section is my interview with Viola about such matters.



Figure 1. Viola Thiele (left) and Isabel Reiss (right) as Mosh Mosh, photo shoot for an interview with the Swiss women’s fashion magazine *annabelle* (2009). ©Karin Heer.

Nina: Can you describe your disability? Were you born with it and, if not, when did you acquire it and was it difficult to adjust to it?

Viola

My condition is plus size, fatness, overweight—or actually nothing really, because that type of monstrosity is a social construct. I got aware quite early that I am a bit more chubby or lumpy than other kids, that kind of stigmatization already started in Kindergarten and continued in school, where kids would make fun of my “huge ass.” Even other parents thought addressing me with pejorative terms would be okay, one father always called me “thick noodle,” probably in order to create a difference to the looks of his own daughter, who was almost as chubby as me. I know that tactic, I actually applied it on some other girl who was more obese than I was, and I joined in picking on her to create a distance to her. I discriminated someone so not to be discriminated. Initially I was told it would be puppy fat and go away, but it didn’t, that condition is simply natural for me. But my mum used to taunt: “Viola hides her beauty behind fat pads,” the quintessence of which being I would be more valuable if I was skinnier. She also believed she herself would be too fat — and she was a mannequin for fashion boutiques! — and still asks my cousin to convince me to diet with her or tries to talk to me about it for “health reasons.” I was always super afraid to go to the school doctor. Until today I am afraid of situations where one is being categorized and measured and weighed.

Nina: How does disability affect your daily life?

Viola

People are obviously quite keen on commenting whenever they see a body with visible anomalies. They feel absolutely legitimated not only to judge your looks, but also to draw conclusions about what shape you are in, what state of health you are in or your general situation, as it is commonly assumed that being fat derives from overindulging, letting oneself go or even forms of self-neglect. I react to that with an inner ambivalence, thinking “I don’t give a hang” on the one side and erecting a wall around myself on the other, so that I do not need listen

to such idiocy. And it is nothing that people only do to children or teenagers. Still today, if people are talking about me and try to specify who I am, they go like — “do you mean her?” (*puffs her cheeks and indicates a large body volume with her arms*). It is also sometimes seen as a sexual fetish, but a very ambivalent one, that is seen as weakness and is used for demonstration of power at the same time. That has happened repeatedly that the adult brats that hang out on the corner of the street near my home are coming on to me. When I gave one of them a sound bite about why I do not approve of this, he yelled after me: “Nobody wants to fuck you anyway, fat pig!” That really got me thinking, how easily those words crossed his lips—it is obviously still okay to discriminate “fatsoes,” everyone agrees with that, as of course, it “is their own fault.” I also know that among young girls that insult is considered worse than “slut” or “bitch.” I do not know any other form of discrimination that still is as widely socially accepted and internalized as that of obese people. Maybe ageism.



Figure 2. Viola Thiele (left) and Isabel Reiss (right) performing as Mosh Mosh during one of the « Nomadic Nights » at Fondation Cartier, Paris, dedicated to the film « Blutbad Parade » by Pauline Curnier-Jardin that Thiele is starring in (2015). ©Olivier Ouadah.

Also, you are being permanently reminded of that by the fashion industry or even objects or architecture. It is being discriminated by objects that are not intended for people like me to use them. And surely, I find clothes, but you are not allowed to choose what you wear. You simply wear whatever you find. Yet then you have designers like stupid Karl Lagerfeld publicly say things like “I do not want a fat [dress size 42] to wear my clothes,” and the media broadcasts that. It has become a bit better in the past years, with “fatshion” blogs and plus size models. But still, just look at all these dehumanizing TV shows, not just Heidi Klum and “Germany’s Next Top model” and the like, but all these casting show formats that disassemble the participants into single pieces. No matter what it is, whether you are not thin enough or sing out of tune, a malicious glee about your incompatibilities gets publicly endorsed.



Figures 3. and 4. Viola Thiele, overpowering Pauline Curnier-Jardin during Mosh Mosh’s performance at a «Nomadic Night» at Fondation Cartier, Paris, dedicated to Curnier-Jardin’s film « Blutbad Parade » (2015). ©Olivier Ouadah



Nina: Do you ever feel ashamed or guilty because of your disability? Or is there even some advantage about it?

Viola

As I already described, the experiences related to my “condition” are almost entirely about body shaming. But my work with “Mosh Mosh” (2007) is my outlet for the experiences I have in daily life, we turn it around and dedicate it to body positivity. “Mosh Mosh” is an electro-glam-fem-trash-performance duo that consists of me and Isabel Reiss, our shows are based on self-written electronic music songs that we sing, dressed in costumes. The project does not scream “Wow, fat positivity!” It is more about a diversity of bodies, or diversity in general, we want to point to alternatives, alternatives in lifestyle, in politics. We do all kinds of things that are deemed socially unacceptable. We play with expectations and normativity linked to a mainstream social narrative, and especially with images that girls and women get assigned to. Girls are supposed to be innocent, well-behaved, beauty-pageant-oriented—these divisions also have economic aspects, there is a whole industry behind that, separate markets for boys’ products

and girls' products. In the videoclip to the song "Lovely & Nice," for example, we do not dress up as you might expect one does for a music video, but we show the non-glamorous reality of our bodies. It deals with the idea of ladylikeness, we put on make-up, we use mascara, but we do not only apply it to our eye-lashes but also onto our teeth, exactly in order to play with and crack those images. In our shows, we also deconstruct this artificial kind of glamour, we go from gala-style divas—who already display certain disruptions—to full-on punk style chaos. We do all kinds of ecstatic "stage acrobatics" like crawling over the floor, jumping on tables, climbing on cars outside the venue, Isa is riding on my shoulders through the audience or attempting to do stage diving—possibly without being caught (*laughs*). I am quite fit, but if someone is not super skinny and wiry, people can often not believe what you are able to do, like doing the splits, or climbing up the loge as I once did in a Berlin club. We are aiming at a reaction when people say, "she isn't really doing that, is she?" And then we double down.



Figure 5. and 6. Left: Thiele, conquering the bar during the performance of Mosh Mosh at SUPERBOUM 7, le Stakhanov, Nantes (2012). Right: Thiele carrying an alleged art critic on her shoulders during Mosh Mosh's opening act for the Swiss pavilion at Venice Biennale (2013). ©Mosh Mosh archive.



Nina: How does your disability influence your work—practically but also topically? Was it relevant for choosing a profession in the art field? Would you make a different kind of art if you did not have that disability?

Viola

Becoming an artist on the one hand was the wish to fit in somewhere, as I always felt a bit excluded and never really belonged somewhere. On the other hand, being an artist enables you to freedoms you otherwise would not enjoy. It was some kind of forward escape, turning one's flaws into a strength or even promoting it as a uniqueness. For example, the French artist Pauline Curnier-Jardin casted me for her work *Bloodbath Parade* (2015), a surreal video about a real circus that was accidentally bombed out during World War I, for the role of the circus director. She always produces very strong images and body images, and underlines that with glamorous costumes and an overall "extrovert" aesthetic. And a certain reminiscence to the historic movie *Freaks* (Browning, 1931) was very likely intended. But I was never able

to reach that all by myself, this idea of “harvesting” one’s flaws, I always needed the context of a group for that. When I am with a group, those are the moments when I feel strong, whereas when I am alone, I tend to behave in a way so that I am not attracting attention, simply pursuing my everyday activities and not aiming to stand out. My stage persona “Lady Mosh” is a different person than Viola, it is almost like walking in someone else’s shoes or lending my body to a person who deals totally differently with it, in a way, which I am not “allowed” to.

Nina: Do you feel that you have to hide your disability from colleagues, or do you openly talk about it? If not, for what reason? Do you have the impression that disability is accepted in the art world and complies with the notion of the artistic genius?

Viola

I do speak about my “fatness,” just not necessarily with people from the art world. A general acceptance of body positivity has very well arrived here, but rather in relation to the idea of diverse bodies and not in relation to fat bodies. Even when speaking to my artist friends I often reach the point where I realize there is in no way for a larger open-mindedness, they are part of the same system of thought as everyone else. Although they know which topic I have been dealing with for years and how much it affects me, they still complement each other in front of me like “Oh you look good today—so slim!” and so on. There is only very little understanding for how bad it is to reproduce certain biases and images. Of course, there is a general understanding that it is not okay to discriminate people. But even if people say to me that it would not matter to them if someone is corpulent or skinny and that they would not regard fat people as ugly, they still live their own lives according to this meta-narrative and try everything to lose weight for whatever reason and keep making these shady compliments. And even I myself always need a moment to step out of that stereotyped thinking, I do not exclude me from that. There is no such thing as an “outside,” I am part of this society, it is very important to be aware of that and accept that.

But the concept of the genius is anyway not relevant to me. Maybe that has to do with the fact that, to me, the construction of the genius always has a male connotation, it is a very outdated idea. I do, in fact, sometimes think “hey, that is ingenious” in relation to intellectual outpourings that people have. But I regard that as rather being something connected to the field of inspiration. If you read that notion of the genius the other way around, it is about people who “always stay in character,” who do not have an “everyday self,” who are always these “ingenious” artists, sparkling with inspiration and great ideas and sweeping others along.



Figure 7. Viola Thiele taking the performance outside into the rainy streets and doing the splits on a sidewalk during a performance of Mosh Mosh in context of the exhibition « Screen Realities » at IG Bildende Kunst, Vienna (2010). © Mosh Mosh archive

I just think that has to be a construction, that does not really exist, except for, maybe, if you are maniacally driven, I do not know if that is being a genius or having a condition. I am aware that this comment is not exactly scientific, but I know such artists personally who have quite an aura which they probably also “cultivate” to a certain extent in order to fit an image—but of whom I also know that there is a crack in that image.

Nina: With the concept of the genius and ableism yet appearing to be generally still such constitutive elements to the predominant notion of art, do you have hopes there will ever be a change of perspective in the art world? Do you have any specific wishes, ideas or even action plans in relation to all that?

Viola

Yes, I will work as an art teacher at a state school from 2019/20 on.

Nina: Sounds like a perfect place to work as influencer. Good luck and thanks a lot for the interview!

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