

“To Be Rather than To Seem: Claiming Identity in Disability Art, Curation, and Culture”

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The title of the show currently on display at the National Humanities Center is titled after the North Carolina state motto: *Esse Quam Videri*, or, “To be, rather than to seem.” And in fact, disabled people have been made to seem many things they are not in representation for a long, long, time. So, there is a real challenge for those of us interested in the intersection of disability and art: depicting disability more expansively in an age where it seems we already can look at the body in every conceivable manner, through means both medical and media-driven. How can we imagine disabled bodies as they *are*, not as what we make them *seem*? Paradoxically, the most vulnerable bodies among us remain invisible even as the popular imagination fixates on depictions from overachieving “supercrips” (look at how much the recent Nike ad featuring Colin Kaepernick features disabled superhumans) to transhumanist fantasies about making the human body better, faster, and stronger through technology. Either way, we are projecting our own desires on those bodies, making them mirrors of our own hopes and fears. By contrast, disability and the arts remain a powerful, vital means to turn us away from the seeming toward disabled being(s). The artists of *Esse Quam Videri* invite a more intense look at the bodies that compel artistic creation and how we view them; yet disability is often unexpected as the matter maker and the made matter of art.

I am an English professor at Davidson College who loves working at the intersection of disability studies and visual representation. I teach about disability in literature and drama, graphic novels and disability, and have co-curated three previous exhibitions reflecting the intersection between disability and art: *RE/FORMATIONS: Disability, Women, and Sculpture*;

Staring, based on Rosemarie Garland-Thomson’s book on disability and the stare (*Staring: How We Look*); and *Re/Presenting HIV/AIDS*.¹ I was honored and excited to co-jury this show, *Esse Quam Videri*, with Linda Dougherty, chief curator of the North Carolina Museum of Art. Our state motto seems particularly relevant in thinking about representing disability experience: “To Be, Rather than to Seem.” As a curator, I continually ask: what do works about bodily difference—by disabled and nondisabled artists alike—show us about the lived experience of disability? How do they challenge what we think we know about the body, and resist how we replicate and recirculate more problematic beliefs? How do these works use disability aesthetics (more on that in a moment) to challenge conventional representational tropes? And in recognizing this, can we move to see disability in visual art as another example of what Garland-Thomson calls “disability gain,” that is, evidence of disability as a force for creativity and the generation of new ways of imagining the world and all bodies within it?

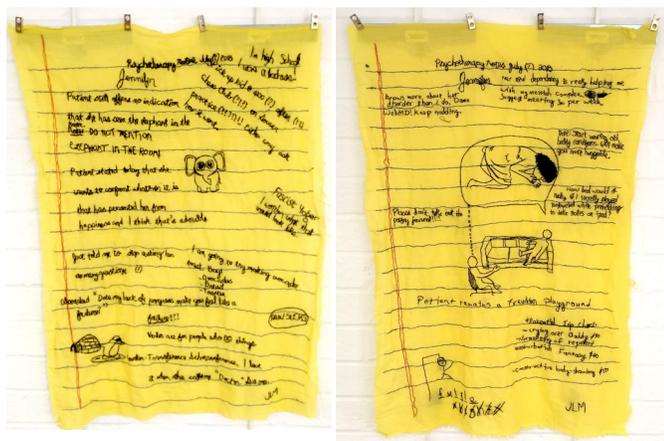
To do this, we need to consciously put aside other, more popular ways of regarding disability in art. For example, art therapy is an important force for healing and expression but is not the only place where disability and art intersect. Critics and curators also tend to ignore the cultural and social aspects of the disability experience, and disability as an aesthetic quality of art. While an artist might be described as having accomplished “in spite of” disability, the extent to which she might have created through and because of disability is often left unexamined. For example, there was no mention in the blockbuster 2014 MoMA retrospective of Henri Matisse’s cut-outs that this medium grew out of the artist’s need to use a wheelchair after abdominal surgery. Medical

¹ The online exhibition catalogue for *RE/FORMATIONS* can be viewed at: <http://academics.davidson.edu/galleries/reformations/index.html>; the catalogue for *Re/Presenting HIV/AIDS* can be viewed at: <https://drive.google.com/open?id=1FFtZ-n64LnmH52Sypsw6Zw9pMKx8DV0A>

schools have combined disability and art in a utilitarian way, using artgoing to train their students in a careful diagnostic gaze that will be transferred to disabled bodies; but does that same looking (or artwork, for that matter) consider the lived experiences of the bodies that will be so carefully scrutinized?

Instead, we might explore the intersection of disability and art in other, more meaningful ways, raising questions many of the North Carolina artists featured in *Esse Quam Videri* explore. How is living in a disabled body understood in a specific place and time? How can the experience, social and embodied, of living with a disability be portrayed? How can art push back against stigma and stereotype, interrogating ideas about bodily normalcy? How can art recast our view of beauty through the invigorating force of disability aesthetics? Our exhibition offers some answers to these questions, as the following examples of works selected from *Esse Quam Videri* suggest.

Jennifer Markowitz's *Notes from My Psychiatrist* compellingly portrays psychiatric/mental disability in a way that sidesteps old tropes of fear/terror. The wall text explains that these two panels of hand-embroidered yellow cloth are meant to represent handwritten notes: "The legal pad is scribbled and doodled on as Jennifer has transcribed these imagined notes written from the perspective of her 'shrink.'" As we see from the notes, that imagined medical professional is smug, certain they know best, and only half listening to the patient. That these "notes from my psychiatrist" constitute a kind of stitched sampler is intriguingly subversive. Samplers are traditionally a domestic space meant to record sweet truisms, bible verses, and other kinds of encomiums. But



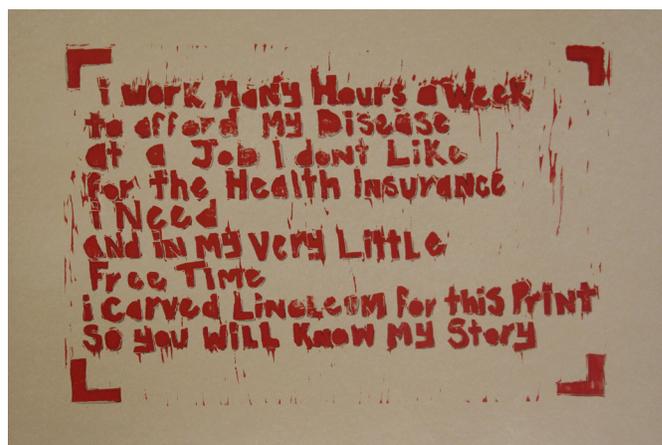
Jennifer Markowitz, *Notes from My Psychiatrist*

on this sampler, the notes are also a kind of exposé. Is this meant to be a critique of the advice of this doctor, too firmly being stitched into place? Are these words the patient is trying to fix into place as a warning to others? Markowitz's use of a sampler, something soft and pliable, dressed up like a personal legal pad somehow softens the cold tablet on which symptoms are being recorded as pathology, and picks apart the presumed good of cure. This is no domestic, identity-erasing sampler; rather, it is a sampler that reveals something previously hidden about the truth of treatment: it can be a place where the patient feels powerless or dismissed.

Cara Smelter's linoleum-cut print *Affording my disease* is focused on the economic/social aspects of disability, something the nondisabled public doesn't often think about other than perhaps through the lens of charity. The print is a micro-memoir on which Smelter has inscribed the following narrative:

I work Many Hours a Week
to afford My Disease
at a Job I don't like
for the Health Insurance
I Need
and in My Very Little
Free Time
I carved Linoleum for this Print
So you Will Know My Story

This work emphasizes that it is important to hear their stories from disabled people directly; as the disability rights movement emphasizes, "nothing about us, without us." Smelter pushes back at the traditional stories of charity, cure, inspiration, or overcoming around which



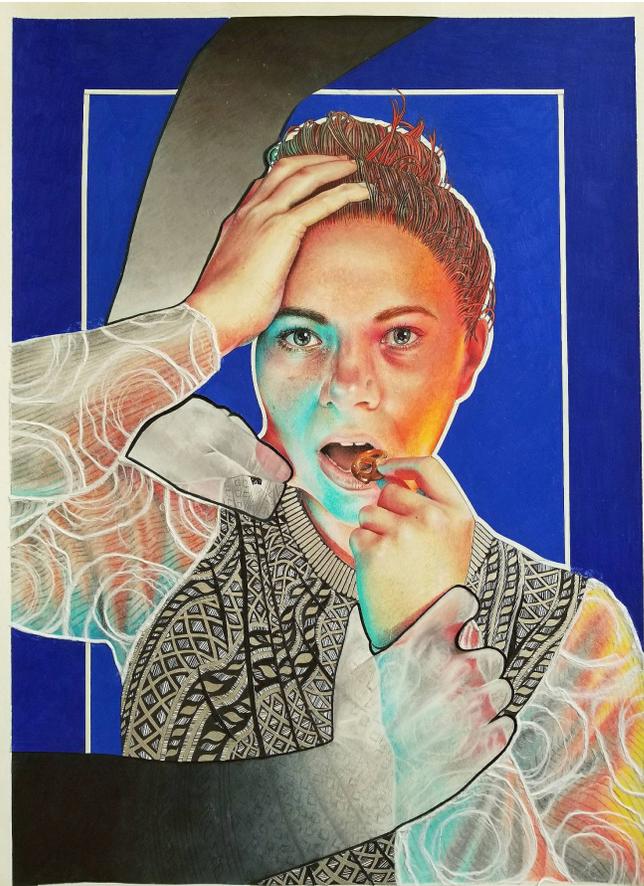
Cara Smelter, *Affording my disease*

disability depictions typically circulate. Rather, the artist is eking out a non-artistic living to afford health care and wants you to know that. Is health care a benefit, the work seems to ask, or a right? Reminding us that it is economics and not disability that have inhibited the artist's work, this print compels us to ask: what art have we lost from this person because they barely have time to simply make this single linoleum-cut print, let alone do anything else? And by extension, what creativity have we lost from disabled people who are limited not by their bodies, but by the social and economic circumstances in which they find themselves? Smelter adds about her work:

I prefer linoleum and block printing as I enjoy the natural variations that come with each print. The medium itself, for me, reflects the imperfections of life. For this exhibition and the pieces included, it is quite perfect as I see the imperfections in my prints as physical manifestations of my body.

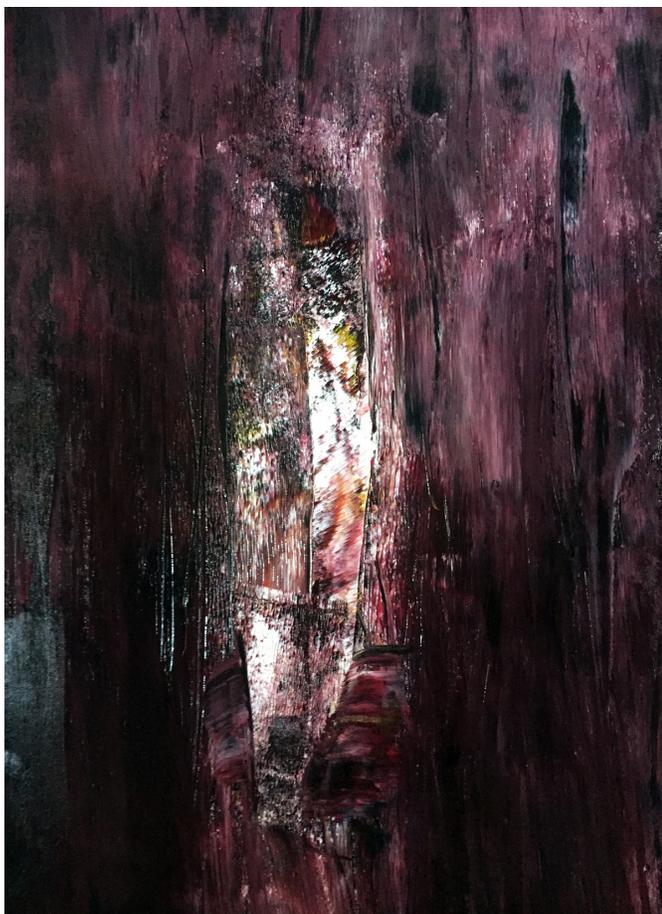
Smelter's comments remind us of the materiality of disability present in her work and others; the variegated nature of this print, resisting neat and ordered typeface, reflects the exuberant, though not always easy, variability of the disabled body.

Shelby Scattergood's portrait *Untitled* visualizes embodiment in a strikingly different way, evoking both the body and the mind in her imagery to show what the artist calls her "daily struggle with Binge Eating Disorder (B.E.D.), the stigma surrounding the disorder, and the condition's everyday realities: conflicting emotions, the compulsion to eat and self-critique, and the desire to hide weight changes." In the painting, a lushly enflashed woman tries to eat, but hands press down on her shoulder, adding the weight of stigma by seeming to define as deeply transgressive her attempt to eat even a small pretzel. As hands immobilize her from above, another hand reaches up from below to grab her wrist and make even this small attempt at self-nourishment a struggle. We might not think of fat as a disability *per se*, but as Scattergood reminds us, it holds much in common with disability experience, as in this depiction of body shaming. Fat, like disability, is heavily policed and medicalized; even though we now know there can be complex emotional, physical, and/or genetic causes at the root of obesity, our society still pathologizes it as an "epidemic," vilifying the individual who we presume would be "cured" if they would "just" stop eating.



Shelby Scattergood, *Untitled*

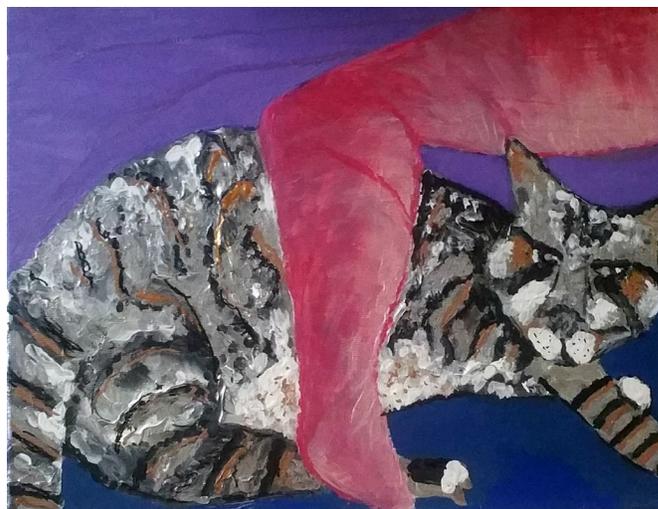
Can there be disability at play in a work that has no clear image of or direct reference to the body? The abstract quality of Anthony Garcia-Copian's *Turning Blues into Purples*, lovely and haunting, suggests the answer to this question is an emphatic yes. Garcia-Copian explains of his work, "When I paint, I paint abstract memories. Sometimes the memory is foggy and has been replaced by an imaginary sediment, a residue that has made one memory solid and the other fluid." As I gaze at the painting, I find that its play between fluidity and solidity takes on other meanings for me as well. Is the wordplay on "the blues" meant to connote depression? Does the fact that those blues morph into purple connote figurative, or even literal bruising? This canvas eludes an easy diagnosis, suggesting the experience of a bodymind in its totality, rather than either just the depiction of body or mind. The painting evokes disability aesthetics, a concept first forwarded by scholar Tobin Siebers. To Siebers, we cannot understand modern art without understanding that disability is integral to creating what we find beautiful within it: fragmentation, distortion, and the disruption of static bodily ideals as a source of pleasure and possibility. An attention to disability



Anthony Garcia-Copian, *Turning Blues into Purples*

aesthetics also prompts us to value art that reconfigures our understanding of how we look at the extraordinary or different. In the case of Ann Millett-Gallant's painting *Spooning with Mama*, her differently figured arm, gently cradling her cat, is foregrounded. Gallant's limb is not cast as spectacle or deviance; it simply is there, engaged in the quotidian: cuddling a cat. And there is pleasure in that connection, for which normate limbs and hands are irrelevant. Indeed, as Millett-Gallant has pointed out, the cat even seems to stare indignantly at the viewer. "What are you looking at?" his look seems to ask, inviting us to examine our own viewing habits and reconsider what about this image might strike us as startling or extraordinary.

Art of the kind in *Esse Quam Videri* unexpectedly but importantly connects us to the lived experience of disability, and by extension, to the bodily contingency and vulnerability at the heart of all our humanity. It raises



Ann Millett-Gallant, *Spooning with Mama*

questions about who gets to make art and refuses the old divide of "insider" versus "outsider" art. Empowered by the imaginative possibility of disability, these artists look at the body slant, disrupt overdetermined ways of looking, and bring disability into being rather than seeming. Cara Smelter describes the importance of this visual exchange in this way:

Discussing disability aesthetics then becomes so important because it enables people to think about the beauty and importance of disability represented in modern art, but also helps folks to think about the human aspect of aesthetics and what implications our questions, rhetoric, and actions may have on bodies that are different from our own. So, I view this conversation here and now about disability aesthetics as significant and important because the more often we discuss appreciation of disability found in modern art, if art is a manifestation of life and is a body in and of itself, then we can facilitate greater understanding and appreciation for the different, unique, and quite honestly extraordinary human bodies we encounter daily.

I invite you to come wander the exhibition and to imagine the ways in which it brings disability into being in your mind as a lived experience and aesthetic value in new and transformative ways: I promise you won't be the same when you leave.