

Pedagogy, Image Practices, and Contested Corporealities

Edited by
Sarah Brophy and Janice Hladki

Pedagogy, Image Practices, and Contested Corporealities

This volume focuses on popular film, television, and online representations of contested corporealities and contributes to visual culture studies, disability studies, critical pedagogy, and medical humanities. Emphasizing unruly embodiments that transgress and transform, the volume conceptualizes visual culture as a space of query and accountability. In their introduction, the editors underline how spaces of cultural production provide necessary contexts for analyzing the social impact of contested corporealities. Contributors, in turn, offer new perspectives on technologies, disability, and cultural production. Eunjung Kim argues that life-size dolls in contemporary art films show how acts of caring for radically passive bodies can emerge as both erotic and beautiful; Nicole Markotić critiques the prioritizing of death as the most desirable, logical outcome in biopics of disability; and Katherine W. Sweaney's article on the online anatomization of an amnesiac's brain reminds us of the high stakes for medicine and science in the public display of knowledge-making. Working at the intersection of fat studies and critical race studies, Scott Stoneman discusses the body politics of the film *Precious*. Katerie Gladdys and Deshae E. Lott reflect on their lyrical installation about life with mechanical ventilation, and Ann Fudge Schormans and Adrienne Chambon examine how image-making by persons with intellectual disabilities can intervene in ableist-defined social space. With attention to queer theory and transnationalism, Michael Gill considers the British web-based RTV program, *The Specials*, where young men labeled as intellectually disabled fashion their erotic self-understandings as they discuss and appreciate an ensemble of Thai *kathoey* performers. Concentrating on the global politics of organ transplantation, Donna McCormack critically examines feature films that mediate questions of community, ethics, and mobility. The volume is further enriched by an interview in which Danielle Peers, Melisa Brittain, and Robert McRuer discuss the significance of crip possibilities in art and academia.

This book was originally published as a special issue of *The Review of Education, Pedagogy, and Cultural Studies*.

Sarah Brophy is an Associate Professor of English and Cultural Studies at McMaster University, Canada. She is the author of *Witnessing AIDS: Writing, Testimony, and the Work of Mourning* (2004) and of essays in *End of Empire and the English Novel since 1945*, *Contemporary Women's Writing*, and *Literature and Medicine*. With Janice Hladki, she has co-edited the volume *Embodied Politics in*

Visual Autobiography (2014). Her collaborative work includes exhibitions on political video art and self-portraiture (2010, 2014–15) as well as a co-edited special issue of *Interventions* (2013).

Janice Hladki is an Associate Professor of Theatre and Film Studies, School of the Arts, at McMaster University, Canada. With Sarah Brophy, she has co-edited the volume *Embodied Politics in Visual Autobiography* (2014). Recent publications include the exhibition book, *Fierce: Women's Hot-Blooded Film/Video* (2010) and essays in *Feminist Media Studies*, the *Journal of Literary and Cultural Disability Studies* (with S. Brophy), and the *Journal of Global Studies and Contemporary Art*. Her recent curatorial work includes *Fierce*, and, with S. Brophy, *Scrapes: Unruly Embodiments in Video Art* (2010–2011) and *This is Me. This is Also Me* (2014–15).

Contents

<i>Citation Information</i>	vii
<i>Notes on Contributors</i>	ix
1. Introduction: Pedagogy, Image Practices, and Contested Corporealities <i>Sarah Brophy and Janice Hladki</i>	1
2. The Ends of the Body as Pedagogic Possibility <i>Tanya Titchkosky</i>	8
3. Why Do Dolls Die? The Power of Passivity and the Embodied Interplay Between Disability and Sex Dolls <i>Eunjung Kim</i>	20
4. Augmented Spirit/Extreme Embodiment: A Mapped Landscape of Vent Life <i>Katerie Gladdys and Deshae E. Lott</i>	33
5. The Reworking of Spatial Attribution: People with Intellectual Disabilities and the Micropolitics of Dissensus <i>Ann Fudge Schormans and Adrienne Chambon</i>	49
6. The Narrator Witness: Dis/Connections Between Disability and Death <i>Nicole Markotić</i>	62
7. Crip Excess, Art, and Politics: A Conversation with Robert McRuer <i>Danielle Peers, Melisa Brittain, and Robert McRuer</i>	74
8. <i>The Specials</i> Meet the Lady Boys of Bangkok: Sexual and Gender Transgression and Smashing Intellectual Disability <i>Michael Gill</i>	82
9. Intimate Borders: The Ethics of Human Organ Transplantation in Contemporary Film <i>Donna McCormack</i>	96
10. "The Most Famous Brain in the World": Performance and Pedagogy on an Amnesiac's Brain <i>Katherine W. Sweaney</i>	110

CONTENTS

11. Ending Fat Stigma: <i>Precious</i> , Visual Culture, and Anti-Obesity in the "Fat Moment" <i>Scott Stoneman</i>	123
12. Afterword: The End of Contested Corporealities <i>Robert McRuer</i>	134
<i>Index</i>	139

Augmented Spirit/Extreme Embodiment: A Mapped Landscape of Vent Life¹

Katerie Gladdys and Deshae E. Lott

What are the consequences of fixating our gaze upon the machine? Are we like Ovid's Pygmalion, who so romanticized his statue that he replaced extant human relations with a supernatural one? Alternatively, do we subscribe to fictions like those exemplified by Doc Ock in *Spider-Man 2* (Raimi 2004), the Borg in *Star Trek: First Contact* (Frakes 1996), or even Maggie Fitzgerald in *Million Dollar Baby* (Eastwood 2004), through which we project such irresistible, unmitigated power upon the apparatus that we doubt its constructive contributions to our lifestyle and fear its role in our communities? Our cultural narratives suggest that we often forge dangerous connections with creations that, in our imaginations, border between two realities: the objectified subject and the fantastic. We begin responding to machines that bridge those realms in ways that compromise or obscure our sense of humanity. Certainly, as Donna J. Haraway (1991) asserts, "human beings, like any other component or subsystem, must be localized in a system architecture . . . Communications technologies and biotechnologies are the crucial tools recrafting our bodies" (163–164). Yet, when the unfamiliarity with or data-production generated by a machine dominates relationships with the human body, interpersonal relationships can become pre-scripted by the interface in ways that discount the human mind's positive creative powers—something we accept more readily when machines (e.g., cell phones, computers, and touch pads) appear outside of medical contexts or accessorize rather than meld with the human form. In the collaborative artwork *Augmented Spirit: Extreme Embodiment*, we highlight fragments from Deshae's life text in an effort to achieve our artistic missions. Debunking human-machine melds as fantastical or impersonal, this investigation uses an interactive sonic art installation to poeticize both the uncomfortable and aesthetic aspects integral to the life of a mechanical ventilator-dependent individual. The sustained life becomes a locus for recognizing that our fascination with the supernatural capabilities of the machine in fact translate into something very basic: a high-maintenance form of survival that presents acute vulnerabilities and impositions as well as ordinary celebrations

of life. This collaborative artwork seeks to activate the observer, the observed, and the social infrastructure toward co-constructing a polyphony that, if not harmonious, goes beyond any cacophonous, fantastic, and horrific stereotypes that characterize dominant cultural narratives on disability and its accompanying apparatuses.

Trach cuff deflated; Remote to "noise maker" stored²

According to John J. McDermott (2006), "medical technology, despite its brilliant, startling successes, cloaks a pervasive sense of interpersonal distance, loss of personal control, and often subjects us to an impersonal paternalism" (255). Our sonically interactive, textile-based art installation specifically challenges assumptions about what constitutes positive human-machine melds by uncovering traces of the life embodied alongside the machines. As relational art, *Augmented Spirit/Extreme Embodiment* translates a particular set of social relations that exist in the world (in this case Deshae's world as a ventilator user) into an art piece that asks the audience physically to participate in or locate themselves in or enter into an intersubjective relationship with the ideas presented and their relationship to the larger ideas that the art intimates (cf. Bourriaud 2002). In our case, the relational art piece challenges and stimulates perceptions about how one turns disability into a creative act not just as a piece but as a life lived.

Rotating mattress overlay & oxygen concentrator turned off

For all of the disconnections persons can attribute to technology, technology continues to create new, accessible interpersonal and global connections among many of us, whether for work or recreation, protest or service. Haraway's "A Cyborg Manifesto" (1991) is prophetic about such possibilities:

Writing is pre-eminently the technology of cyborgs . . . Cyborg politics is the struggle for language and the struggle against perfect communication, against the one code that translates all meaning perfectly, the central dogma of phallogocentrism. That is why cyborg politics insist on noise and advocate pollution, rejoicing in the illegitimate fusions of animal and machine. These are the couplings which make Man and Woman so problematic, subverting the structure of desire, the force imagined to generate language and gender, and so subverting the structure and modes of reproduction of "Western" identity, of nature and culture, of mirror and eye, slave and master, body and mind. (176)

The cyborg—both as a myth and as an actual hybrid of human and machine—restructures misrecognitions into re-cognitions by disassembling and splicing dominant discourses with alternatives that reconstitute how we perceive and articulate embodied reality. However unnatural the fusion of woman and machine, lives now transgress such boundaries.

In bed, physical therapy/passive range of motion, round 1 of 3

Health machinery born of advancing medical technology inspires new understandings of cyborg existences. Vent-user Deshae Lott's life demonstrates the complications and triumphs that emerge in using technology to sustain life

and invites others to locate embodiment and commonality amidst the biomechanical and unusual. The machines necessary to sustain her life—ventilator, suction canister, oxygen concentrator, wheelchair, chest vest, in-exsufflator, nebulizer—(Lott 2011) whoosh, whirl, alarm, drone, buzz, vibrate, chime, and tone around her, creating interfaces of intrusive, cumbersome, and cacophonous tubes and devices that seem antithetical to personal freedom. The frail body and the engineering feats that sustain it demand unrelenting attention, yet, in this case, the very presence of an individual life connected to the interfaces fosters a creative process whereby the patient and caregivers cooperate with the interfaces without being dictated to or dominated by them. Interdependencies with machines, people, and systems add texture to the song while Deshae's voice carries the melody and, faint though it is, vibrantly arises amidst and because of the interfaces. Through the use of interactive textiles, we present a multilayered sculptural installation mapping how the human consciousness, sustained by medical interfaces, emerges to create meaningful connections with others and the surrounding environment. Viewers of the piece will be led, as persons are in Deshae's presence, to see the life itself in the foreground, rather than the unfamiliar and imposing infrastructure sustaining that life.

Detachment from bed-side vent; transfer body, bed to chair

IMPETUS FOR THE COLLABORATION

Our academic fields intersect in the study of how individuals shape and respond to processes that become part of a community's landscape.

Attachment to wheelchair vent; bed-side vent moved by toilet

Deshae Lott, a person with one of the two most severe forms of Limb Girdle Muscular Dystrophy, uses her own life as a malleable medium. In her published articles and public speaking engagements, she creates a lexicon inspired by her physical condition in order to invite others to enter her landscape. Deshae finds ways to allow difference to strengthen both the individual and the community. Then, through spoken, written, or typed words and other physical expressions, she proposes approaches for understanding and constructively responding to such differences. An activist practice emerges from the text of her life. Although one experience, such as hers as a vent user, can never represent the full range of human experiences because each life has unique elements, the whole can be better understood by explorations of its disparate parts. Even if her story serves as but one model—and one that cannot speak for every person living with a disability—Deshae combats misunderstandings about disability that lead to exclusion. She disassembles and creatively reassembles factual evidence (images and sounds and patterns) from her environment and life, arguing that even when disability disrupts familiar patterns and rhythms, the fostering of inclusion benefits both individuals and communities.

Wheelchair & vent batteries unplugged from their chargers

Exploration and the literal path-less-traveled inform Katerie Gladdys' art practice. Her work transforms mapped landscapes and familiar interactions into alternative geographies that transform how we experience a place, space, and dynamic. As she transmits her own sense of wonder, she seeks to encourage others to look more closely at what constitutes their everyday existence. Listening to the stories of others allows her to engage the audience in a familiar modality as an entrance into unfamiliar terrain. Cultivating alternative modes of categorizing information opens a discourse that produces new opportunities for problem recognition and solving that have the potential to influence other fields. Katerie endeavors to make art that awakens curiosity about the quotidian in her viewers, transforming spectators into participants yearning to explore their surrounding environments, and perhaps developing their own unique strategies to connect with the world around them.

Bathing & dressing; Tracheostomy stoma cleaned

PROCESS

Augmented Spirit: Extreme Embodiment responds to Jacqueline Ann K. Kegley's (2006) call that we "pay attention to the conditions necessary for creative living even when terminal or ill" (75). In part, we believe such attention can emerge only when our culture understands more about what it means to live with an illness and about the possibilities and resources necessary for creatively inhabiting a body sustained by biomedical interfaces. Kegley attests that medicine "ignores the person's story and its relevance to the healing process":

Josiah Royce and others have argued that the person is his or her story, his or her life-project, and to ignore this is to degrade the person and to trespass on individual autonomy . . . Medicine and medical education have tended to devalue the voice of the patient . . . the patient becomes objectified and rationalized, and the person's lived experience and personal meaning of the illness are ignored. (75-76)

One way of acknowledging the story is by examining the landscape of an individual body and using it as material for art-making, including the art of introducing alternative rhetorics of what it means to inhabit the human body. In this iteration we choose to sonically map some of the social networks and mechanical interfaces Deshae encounters daily.

Oral medications; Respiratory treatment 1 of 4

What becomes vital to responding to Kegley's call is not the structures and machines that sustain life but, rather, how Deshae goes about creating conditions that afford her creative spaces within that essential infrastructure. John J. McDermott distinguishes between our landscape, as that which we inherit, and our personscape, or how we manipulate our landscape with our hands, tools, and modern technology (Hart 2006, 157). Our installation reflects how the inherited landscape and the unique personscape merge and, then, how various

personscapes interact with Deshae's disability and personality in ways that develop new awarenesses and beauties in a difficult landscape. Even though the disability limits the landscapes through which interpersonal relationships emerge, it also expands the community of people with whom Deshae engages. For example, as an Americanist concentrating in religious studies and disability studies, Deshae, with a healthier body, might never have navigated a maze of healthcare exchanges or done so in contexts in which she cultivated more than surface-level interactions with doctors, nurses, hospital advocates, insurance case managers, home health agencies and employees, attorneys, and medical equipment suppliers.

Nebulization, Chest Vest, Cough Assist, Lungs suctioned

Our piece conveys both the fluidity and disruption inherent in a vent user's existence while also capturing, to use Haraway's (1991) phrase, "frozen moments":

Technologies and scientific discourses can be partially understood as formalizations, i.e., as frozen moments, of the fluid social interactions constituting them, but they should also be viewed as instruments for enforcing meanings. The boundary is permeable between tool and myth, instrument and concept, historical systems of social relations and historical anatomies of possible bodies, including objects of knowledge. Indeed, myth and tool mutually constitute each other. (164)

While we present realities of the disease process such as bureaucracies, invasive technologies, and social mores, the project combats dis-ease by inviting the participant to engage the installation in a playful manner. In that play we hope the audience might ask "What is this?" "What does it mean?" and "What does it mean to me?" in such a way that the analysis is neither sterile nor voyeuristic but, instead, an intriguing opportunity to explore potentially unmapped terrain. Just as Kegley calls medical practitioners to listen to their patients' stories, we encourage audiences to listen to and engage with one patient's story through their curiosity about and interaction with the art piece's interfaces. While Katerie works elements of "playfulness" into her various digital installations, in *Augmented Spirit/Extreme Embodiment* such play perfectly relates to and reflects the creative, joyful method by which Deshae approaches her life and disrupts conventional notions of dis-ability.

Leg & arm braces worn to stretch tendons

DAY IN THE LIFE OF DESHAE

With her vent dependency in November 2002, a new series of regular rhythms and movements emerged in Deshae's life. Deshae's survival strategies now dominate her daily schedule, disrupting and restricting its non-health-related activities in unrelenting intervals just as do the lines of text appearing beneath each paragraph in this article, where each such line details aspects of Deshae's

survival routine. This schedule for living—with constricted vistas for productivity beyond survival and maintenance periods—promotes peace, order, and stability in the midst of chaos and dissolution. Deshae's artistry has a two-fold effect: Deshae is able to maximize her situation, orchestrating quality-of-life moments within the limitations imposed by her body and other resources (time, money, energy); and her companions cultivate such a sense of comfort in the spaces where the cacophony of her machines and the dissolution of her body pervade the landscape that, sometimes, they feel greater comfort in Deshae's spaces than in their alternative environments. Her careful management of her lifestyle models the human potential to navigate one's terrain with receptivity rather than resentment. In a pronounced way, the personscape informs and manipulates the landscape.

In chair, physical therapy/passive range of motion, round 2 of 3

MAPPING UNRECOGNIZED SPACE

Much of Katerie's work uncovers and re-presents experiences of marginalized landscapes in the natural world—landscapes that are both very present and accessible but also forgotten or even unrecognized. The mythology of a utopian future inhabited by cyborgs recurs as a theme in contemporary culture and in the content of digital media art. The cyborg exists as part of a future almost here but just beyond our grasp. As both colleagues and friends, Deshae and Katerie have had engaged discussions about disability and creative work. After Deshae became vent dependent in 2002, Katerie became aware of the ever-present apparatuses sustaining Deshae's physical life and how their physical forms recall popular notions of what constitutes a cyborg, or an augmented body. Katerie noticed, too, that the context and purpose the apparatuses serve differ greatly from their fictive representations.

Food and drink; teeth flossed & brushed

AURAL AND VISUAL SPACE OF DESHAE'S HOUSE

Deshae lives in a suburban development where little is unique to the exteriors of the neighborhood houses. In contrast, as one would expect, the interior feels more personalized by furniture, bric-a-brac, and books but still rests within the range of middle-class American expectations. The generic neighborhood belies what happens inside the domestic space Deshae calls home. At the same time, despite the abundant medical interfaces prominent in every room of Deshae's home, the experiences of the visitor prove markedly different from when the same visitor enters into institutionalized home settings such as a group home, a convalescent home, an assisted-living complex, a rehabilitation facility, or even an intensive care room—which Deshae actually now refers to as her "home away from home."

Deshae assisted in restroom—transfers, ventilation, wiping

Due to Deshae's medical condition and its requisite survival apparatuses, Deshae's home and body do present any novice visitor with an unrecognizable landscape. In terms of her body itself, unfamiliar gestures can signal something quite familiar. Deshae cannot lift her arms for hugs, or her hand to shake that of another. A guest must decipher, learn, and re-code that, with Deshae, her palm extended on her wheelchair's armrest is a welcoming gesture. In actuality, a great deal of Deshae's lifestyle corresponds to landscapes that very much pervade the typical person's lifestyle: the neighbor who does not get out much because of health reasons, and so who is only occasionally seen yet still seems as present and real as she is mysterious and unknown; or, more basically, the fellow human being who breathes, eats, drinks, and dwells—sleeping or awake—within a framed housing structure. In fact, Deshae's life is akin to so many of the lives most of us acknowledge on some level. It is to the typical passerby simply the life of another stranger whose unique and challenging story that passerby might never witness up close, as it actually transpires behind the walls and on the walls and beyond any walls at all. Our work invites an audience to engage with a slice-of-life perhaps not previously seen and, thus, to cultivate a deeper sensibility about what being human can entail.

Respiratory treatment 2 of 4

In a domestic setting, Deshae's disability becomes tangible in a two ways that the installation reflects: the traces of literal paths on the carpet that Deshae's powerchair travels from room to room; and the constant sounds of the machines that sustain her life and that contrast with the sounds of everyday living. In Deshae's home, all movement occurs within a restricted space. Restrictions emerge both in terms of the boundaries of the walls of the house and its plot of land, further, in terms of which area of which room contains the specific life-sustaining machines needed at set times of the day. Accordingly, the aural-visual, interactive digital installation poetically represents such an alternative universe and its complexity so that others both learn about restriction and, concurrently, glimpse the creativity that it takes to lead a rich life within limited space. *Augmented Spirit/Extreme Embodiment* thereby captures one potential narrative of the daily life of a vent user.

Mechanical Compression arm sleeve worn for lymphedema

The first evidence of deviance in Deshae's house, which is thus reflected in the installation *Augmented Spirit/Extreme Embodiment*, is the neutral-toned carpet and the traces left on it by her wheelchair. The smudged imprints and compressed carpet fiber reveal Deshae's well-worn path from her bedroom to the kitchen to the living room and, finally, to her study. This path is wider than a foot-path dotted with tufts of upstanding carpet. The path winding through the house forms a kind of map, inspiring artistic play with the evidence of Deshae's movements throughout the house—evidence unique to Deshae's mode and path of locomotion. Traced, this evidence formed a map demonstrating proof of the life lived.

Fresh ballard & heat-moisture-exchange replace day-old set

When some people return to their own homes after spending time at Deshae's, they—like Katerie—may feel struck by the relative quiet as well as the ability to listen to ambient sounds from the outside. At Deshae's house there is constant mechanized sound at any given time: the ventilator itself, its alarm, the periodic suctioning of fluid from her lungs. The din is punctuated by laughter, teaching, conversation, and poetry, as well as the household sounds that we take for granted, such as the buzzing of an alarm clock, the running of water, the flushing of toilets, the churning of the dishwasher, the toning of doorbells, and the ringing of phones. Human beings have designed a host of machines, the working sounds of which deliberately interrupt our lives in order to increase convenience or efficiency. Such sounds arise in Deshae's home alongside an equally large host of sounds from devices required not simply for convenience or efficiency, but to sustain life. Listening to these life-sustaining mechanical sounds as an observer, a pattern or rhythm emerges. The house/space becomes simultaneously a map and an instrument reflective of the creativity with which Deshae approaches her life.

In chair, physical therapy/passive range of motion, round 3 of 3

THE ROLE OF COLLABORATION

Deshae's survival depends on a complicated dance of support people. Her existence is a carefully orchestrated collaboration in which Katerie now takes part. Katerie grapples with the idea of representing Deshae's living space in terms of sound and imagery because the mapping itself is a subjective and limiting activity. Although we discuss the nature and product of the collaboration, the process of distillation and creation requires Katerie, as an artist, to make choices about which situations to represent—and how to represent these situations that are not her own. In a sense, the collaboration doubly functions as a relational artwork, where the artist of the life portrayed reflects on her creativity and her creative process and, at the same time, the installation itself captures glimpses of both the process and the artists' reflections. All the while, we invite the audience to observe this process of negotiations and explorations in hopes that the audience, in turn, meaningfully will negotiate and explore the installation and the ideas it represents, challenges, and celebrates.

Respiratory treatment 3 of 4

The process of collaboration highly informs the nature of the audience's interaction with the piece. The installation ideally provides a place where people have opportunities to learn about the landscape of disability and simultaneously are able to/have to/are compelled to co-create this environment with others. This co-creation allows participants to physically "feel," to some small but measurable degree, the bodily inconvenience and mental irritation of disability during their processes of creating a soundscape unique to their movements even as they encounter the sonic textures added by other persons also moving through the piece. The experience has the potential to become a rich tapestry of sound

and, at the same time, has the possibility to sink into cacophony when two or more people participate and “play” in the space. This reflects the life Deshae leads, where the constant presence of others (machines and human beings) necessary for her survival sometimes feels quite unpleasant, and, at other times, offers such a beautiful scene that the laborious and disharmonious dimensions of the lifestyle slip from the foreground of each co-participant’s consciousness. The installation thus aims to capture the poetic triumphs as well as the chaos and rigorous methods of the vent user’s lifestyle. In both the art piece and the life it represents, this tension between coexistent realities of the vent user’s situation dominates the visual, aural, and interpersonal landscapes.

Food and drink; teeth flossed & brushed; oral medications

DESCRIPTION OF THE PIECE

The physical work consists of a piece of carpet cut in the shape of the floor plan of Deshae’s house. Stitched or embroidered into the carpet using conductive thread are two parallel paths or tracks representing the imprints of wheelchair wheels. On two small-sized versions of the piece, Katerie’s embroidering of the path gestures, additionally, to the domesticity of the environment. The medical apparatus is in full view of the audience, and the juxtaposition of the represented machines against the very domesticity of the installation materials—the carpet and the furniture-like stand with the apparatus—imparts a tension that is inherent in Deshae’s home environment as well as in the environments of other people in her situation who live at home.

Respiratory treatment 4 of 4

Contingent on the space allotted to the installation, the audience’s bodies—fingers, hands, feet, wheels of other wheelchair users’ chairs—come into contact with either or both tracks on the carpet, thereby triggering sets of sounds typical of Deshae’s aural experience in a particular room in her house. The participants navigate the space by simultaneously tracing with fingers or walking/shuffling their feet on the two paths, applying pressure (see Figure 1). Different points on the path elicit different sounds or layerings of sound. Sets of wall speakers that broadcast the various mechanical and human sounds surround the carpet. (The latter sounds may be familiar ones, such as conversations, or unfamiliar ones, such as Deshae’s physical reactions to various machines interacting with her body.) In one version of the piece, portable DVD players boxed to resemble decorative pictures typically hung in domestic interior spaces play video that, on first glance, appears to be an abstracted landscape but that, on closer examination, is the landscape of Deshae’s body undergoing some of her daily therapies. Specifically, the images capture aspects of Deshae undergoing her physical therapy or passive range of motion with the help of her husband (see Figure 2).

Vent moved from beside toilet to bed-side

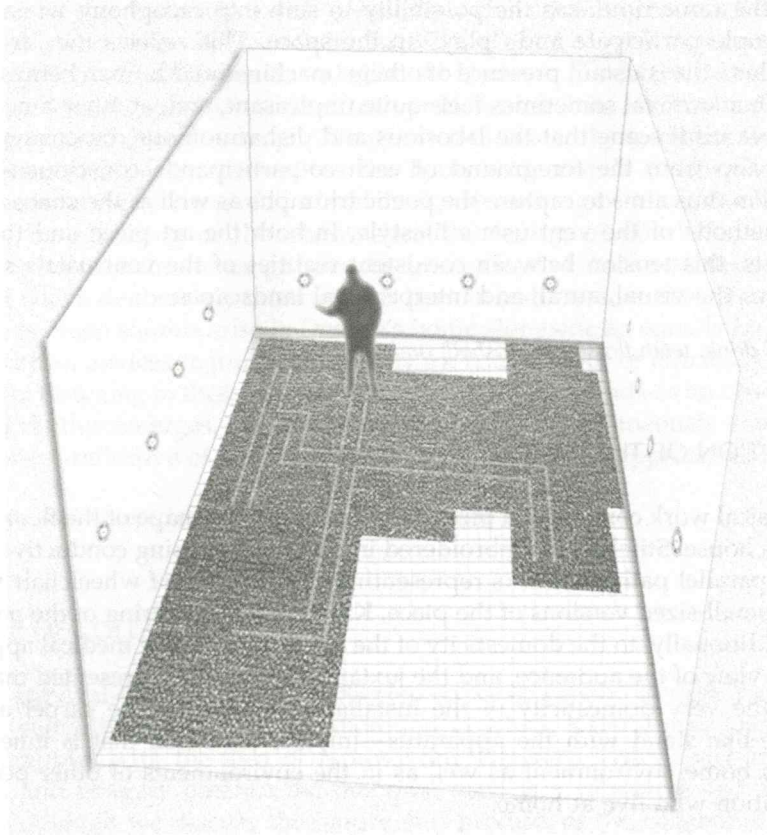


Figure 1. Diagram 1: Participant on mapped path.

Our multilayered sculptural installation represents Deshae's experiences through the use of images hung on museum room walls and sounds emerging from the audience's tactile interaction with textiles centered in that same room; observers become participants (Gladdys 2010). The installation connects something common to many persons' lives (carpet) with a fairly uncommon lifestyle (vent dependency). The impressionist piece ideally invites the listener/viewer/sound-activator to approach alternative realities with curiosity and personal involvement.

Rotating mattress overlay & oxygen concentrator turned on

SIZE AND SCOPE

As it appears in museums and similar fora, this piece is an installation where people walk or "wheel" the paths. This installation is site-specific, so its size and scope typically depend on the location specifics wherever the piece appears



Figure 2. *Abstracted landscape video of Deshae's body undergoing physical therapy.*

for public display/co-performance. Ideally, there would be a large floor space to lay the carpet and walls for the speakers (see Figure 3). The area would allow for both foot traffic and spaces for participating in the installation itself. Currently constructed pieces are sonic sculptures that use the hands or fingers to follow the path and trigger the audio.

Detachment from chair vent; transfer body, chair to bed

MOVEMENT IN THE PIECE

In *Augmented Spirit/Extreme Embodiment*, participants navigate the space by simultaneously placing their feet or fingers on two parallel tracks—representative of wheelchair paths through Deshae's home—and walking or shuffling or tracing atop those paths, following the trail as they desire.

Attachment to bedside vent; Deshae voids via a urinal

The motion of the participant triggers sounds, voices, and noises specific to the sonic environment either of Deshae's home or, sometimes, of homes in general. The restrictions on movement placed both on the space itself (the plane of the carpet) and on the mode of locomotion (having to walk wide-legged or to trace with fingers in order to touch the two tracks and activate more sounds) convey, gently and in a small way, the inconvenience of disability. At the same time, these restrictions evoke the play of a game like Twister, where successful players place their bodies in "unnatural" or awkward positions. The human-body-scaled installation allows the participant to perform/experience disability. And, with both the smaller and larger installations, those who interact with the carpet become part of an electronic instrument where movement encourages the

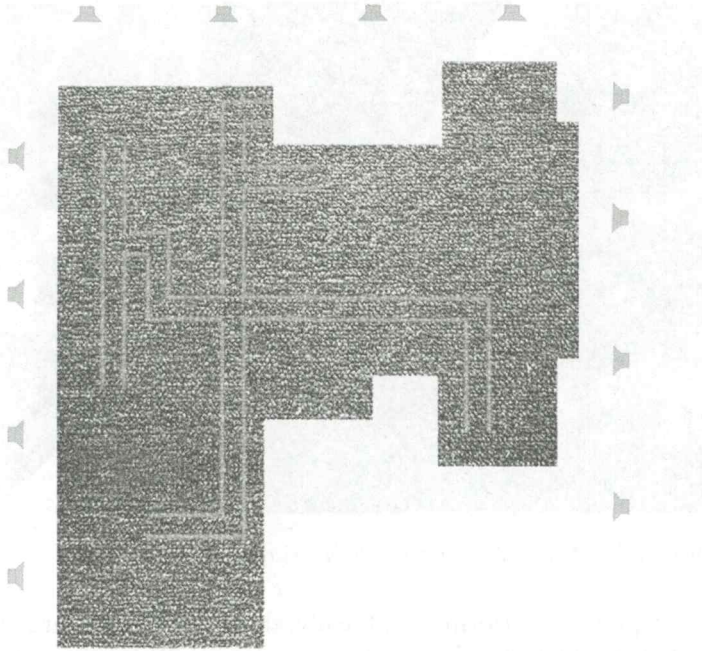


Figure 3. Diagram 2: View from above.

audience to experiment with sound and, potentially, to realize an alternative perspective on disability. Additionally, a video playing on a portable DVD player illustrates the minugia of Deshae's various therapies and makes them into their own landscapes.

Wheelchair & vent batteries plugged into their chargers

TECHNOLOGY AND MATERIALS

The parallel wheelchair tracks are stitched into the carpet with conductive thread. The stitches appear to be different-colored loops in the carpet and variably blend into the weave of the carpet. (Conductive thread does not carry a current that is strong enough to cause injury to human beings; the charge of static electricity potentially created by rubbing carpet in a dry environment is stronger than the current of the conductive thread.) The ends of the conductive thread are connected to very thin wires that lead to a circuit board containing touch sensors. The touch sensors have their own wires, which lead to an Arduino device that is connected to a USB port of a computer running the program Max MSP. Touching the carpet sends a message to the computer to play a particular sound or sets of sounds, which the computer then sends to the speakers via a multi-channel audio interface that sends a discrete sound to a particular speaker.

Deshae given remote that activates her "noise maker"

ART PROJECT DOCUMENTATION

See Figures 4 and 5 for art project documentation.

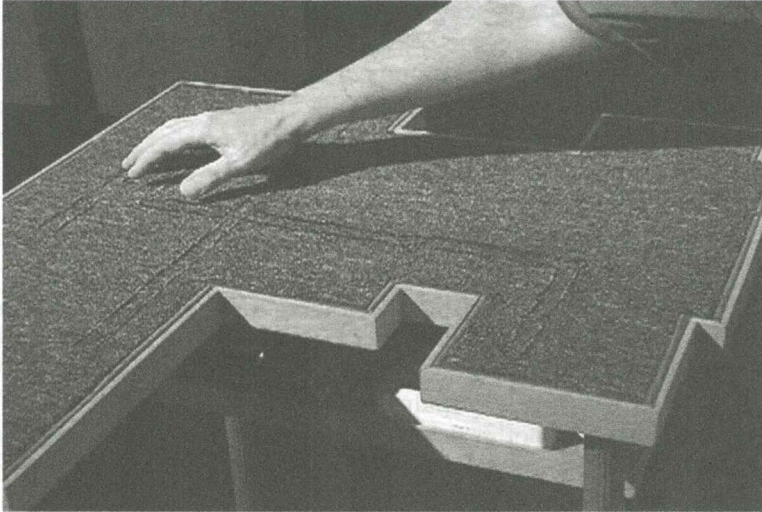


Figure 4. Hand touching stitches. *Augmented Spirit/Extreme Embodiment: Sonic sculpture mapping the interior space of a vent user.*

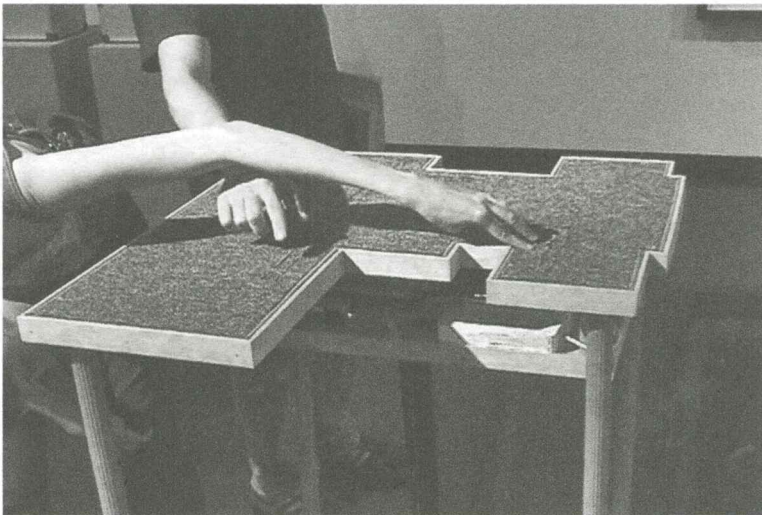


Figure 5. Two participants playing with sculpture. *Augmented Spirit/Extreme Embodiment: Sonic sculpture mapping the interior space of a vent user.*

CONCLUSION

The art project *Augmented Spirit/Extreme Embodiment* tries to connect something common to many persons' lives (carpet) with a fairly uncommon lifestyle (vent dependency); the tangible aspect of the carpet where sounds activate at the touch of a viewer-participant links, in a real way, the more typical human's experience with the ventilator user's more atypical experiences. The carpet, however, serves as only one co-structure shared between the vent user and non-vent user, the artist and the audience. Other co-structures emerge when the audience, through the pressure of touch, triggers familiar sounds of domestic life or the voice of Deshae alongside the unfamiliar sounds. In effect, the audience's own unique physical motions through the installation set off unique sequences of aural sensation.

Trach cuff inflated; lungs suctioned

Like other museum installations, an audience can engage with this piece by reading the tag with its brief description, artists' names, and the related artists' websites addresses. Yet, given the sonic sculptures in the piece, a varied audience is invited to engage with *Augmented Spirit/Extreme Embodiment* by activating sound sensors. In particular, sounds typical to a person's day (e.g., discussions on choices of salad dressing or family member frustrations, silverware hitting a plate, clocks chiming, a toothbrush rubbing against one's teeth) contrast with the roar of the suction canister, the whirl of a rotating bed mat, and discussions about medical equipment. Excerpts from Deshae's autobiographical poems and her teaching seminars also correspond with locations on the map of the house in which such kinds of living occur.

*By twenty-one she had acquired
A decade of practice
Waiting like this,
Waiting
For someone else
To button her shirt
Zip her pants
Tie her shoes
Lift her frame
From a chair, a bed, a toilet, a seat in the van...
At thirty-one she stopped breathing
Without electricity and a machine with tubes and alarms.
Inhalation and exhalation mechanized,
Her nose and mouth and diaphragm became
Mere accessories.
She could not be left alone ever:
A tube might pop loose;
The trach might plug up;
The electricity might go out.³*

Through such interaction with the project, then, we hope to compel participants in a small way to approach realities different from their own with greater curiosity

and personal involvement. Despite any discordant differences that inform and dominate the individual's first impressions, curiosity and personal involvement might help audience members at least to recognize and perhaps even to develop resonance with the very human aspects present in these, to them, unfamiliar situations. One of our hopes is that, by participating in the installation, the audience will experience something akin to the experiences of those who enter Deshae's home. The discordant sounds and unfamiliar machines, dialog, and interfaces slip into the background when a shared humanness emerges and becomes the communal focus. The interfaces gradually lessen their seductive grasp on a visitor's attention; instead, by stimulating the installation and, in turn, being stimulated themselves on a variety of levels (including the very direct sensation of feeling sound reverberations or creating static electricity), the vibrancy of the co-creative human exchange compels all participants' attention. In a way, we use machines to promote and deepen understanding about and empathy for health machinery. Unlike an advertisement, however, we do not promote or endorse a product. Our work seeks to promote personscapes and to suggest that positive outcomes can surface through convergences of dramatically different personscapes. Like much art, the installation proves impressionistic in character, thereby inviting the listener/viewer/carpet-trodder/sound-activator to form unique relations with, and perchance because of, *Augmented Spirit/Extreme Embodiment*.

*Unpredictably, and briefly,
Freedom would return to her.
She could ride in the van to attend
Her nephew's track meet,
Her niece's dance recital,
Her physical therapist's rock concert,
A meal out with friends.
Each time freedom came,
She wept,
Grateful to practice ordinary life again,
Grateful to be present and glad at heart.⁴*

NOTES

1. Acknowledgements of financial support: For conference travel, the University of Florida School of Art and Art History Travel Grant, 2009–2010. And, for material and equipment, the University of Florida College of Fine Arts Scholarship Enhancement Fund, 2008–2009.
2. For more information about Deshae's health care routine, see http://www.deshae.info/health_care/use.htm.
3. Lines excerpted from "The Sick Wife," an unpublished poem by Deshae E. Lott.
4. Lines excerpted from "The Sick Wife," an unpublished poem by Deshae E. Lott.

REFERENCES

- Bourriaud, N. (2002). *Nicolas Bourriaud: Relational Aesthetics*. Paris: Les Presses du réel.
 Eastwood, C. (Dir.) (2004). *Million Dollar Baby* [DVD]. USA: Warner.
 Frakes, J. (Dir.) (1996). *Star Trek: First Contact* [DVD]. USA: Paramount.

PEDAGOGY, IMAGE PRACTICES, AND CONTESTED CORPOREALITIES

- Gladdys, K. (2010). Getting a Lay of the Land. <http://layoftheland.net/augmentedGladdysLott/> (accessed April 4, 2011).
- Haraway, D. J. (1991). *Simians, Cyborgs, and Women: The Reinvention of Nature*. New York: Routledge.
- Hart, R. E. (2006). Landscape and Personscape in Urban Aesthetics In J. Campbell & R. E. Hart (Eds.), *Experience as Philosophy: On the Work of John J. McDermott* (pp. 140–161). Bronx, NY: Fordham University Press.
- Kegley, J. A. K. (2006). Living Creatively, While Terminal. In J. Campbell & R. E. Hart (Eds.), *Experience as Philosophy: On the Work of John J. McDermott* (pp. 58–83). Bronx, NY: Fordham University Press.
- Lott, D. E. (2011). *Description of Deshae's Equipment Use*. http://www.deshae.info/health_care/use.htm (accessed April 7, 2011).
- McDermott, J. J. (2006). Afterword: You Are Really Able In J. Campbell & R. E. Hart (Eds.), *Experience as Philosophy: On the Work of John J. McDermott* (pp. 237–272). Bronx, NY: Fordham University Press.
- Raimi, S. (Dir.) (2004). *Spider-Man 2* [DVD]. USA: Sony.