

## Augmented Spirit/Extreme Embodiment: A Mapped Landscape of Vent Life

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## INTRODUCTION

What consequences emerge when we fixate our gaze upon the machine? Are we like Pygmalion who so romanticizes his creation that he replaced extant human relations with the supernatural one? Alternatively, do we subscribe to fictions like those with the character Doc Ock in *Spider-Man 2* (Sargent 2004), the Borg in *Star Trek: First Contact* (Braga and Moore 1996), or even Maggie Fitzgerald in *Million Dollar Baby* (Haggis 2004), where 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 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.” (1991, 163-164) However, 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 (eg. cell phones, computers, touch pads) appear outside of medicine or accessorize rather than meld with the human form. According to John J. McDermott, “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.” (2006, 255) Debunking human-machine melds as fantastical or impersonal, our investigation poeticizes both 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. Our sonically- interactive, textile-based art installation—which informs this article as well as the museum art piece itself—specifically challenges concepts about what constitutes positive human-machine melds.

*Trach cuff deflated; Remote to "noise maker" stored*<sup>1</sup>

For all of the dis-connections persons can attribute to technology, technology continues to create and provide new, accessible interpersonal, global connections among many of us whether for work or recreation, protests or service. Prophetic about such possibilities, in “A Cyborg Manifesto” Haraway argues that

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.  
(1991, 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.

*Rotating mattress overlay & oxygen concentrator turned off*

Health machinery born of advancing technology in medicine inspires new understandings of cyborg existences. Vent-user Deshae Lott's life demonstrates the complications and triumphs emergent 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) whoosh, whirl, alarm, drone, buzz, vibrate, chime, and tone around her, creating interfaces of tubes and devices whose intrusiveness, cumbersomeness, and cacophony seem antithetical to personal freedom. The frail body and engineering feats to 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. Interdependency 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 environment. Viewers of the piece will be led, as persons are in Deshae's presence, to see in the foreground the life itself rather than the unfamiliar and imposing infrastructure sustaining her life.

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

## 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.

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

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 that difference can 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. While one experience, such as hers as a vent user, can never represent the full range of human experiences since 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, showing or arguing that, even when disability disrupts familiar patterns and rhythms, benefits arise when communities foster inclusion.

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

Exploration and the literal path-less-traveled inform Katerie Gladdys's 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 the curiosity for the quotidian in her viewers: transforming spectators into participants yearning to explore their surrounding environments, perhaps developing their own unique strategies to connect with the world around them.

*Wheelchair & vent batteries unplugged from their chargers*

In *Augmented Spirit: Extreme Embodiment* Katerie and Deshae highlight fragments from Deshae's life text in an effort to reach their artistic missions. Hoping for a residual ameliorative effect emerging from co-constructing polyphony among the observer, the observed, and the social infrastructure, the artists invite the audience to become participants who learn what constitutes Deshae's ordinary existence.

*Bathing & dressing; Tracheostomy stoma cleaned*

## PROCESS

*Augmented Spirit: Extreme Embodiment* responds to Jacqueline Ann K. Kegley's call that "We should pay attention to the conditions necessary for creative living even when terminal or ill." (2006, 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 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. (2006, 75-76)

One way of acknowledging the story is by examining the landscape of an individual body and using that 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 map sonically some of the social networks and mechanical interfaces Deshae encounters daily.

*Oral medications; Respiratory treatment 1 of 4:*

What becomes vital to Kegley's call is not so much structure and machines that sustain the life as how Deshae goes about creating conditions that afford her creative spaces within the essential infrastructure. John J. McDermott distinguishes between our landscape, that which we inherit, and our personscape, 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, the disability 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 to a vent user's existence while cognizant of capturing, to use Haraway's 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. (Haraway 1991, 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 an intriguing possibility 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 period—promotes peace, order, and stability in the midst of chaos and dissolution. The artistry imparts a two-fold effect: Deshae's ability to maximize her situation, orchestrating quality-of-life moments within the limitations her body and other resources (time, money, energy) impose, and her companions' likelihood to cultivate 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 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 the experience 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 the apparatuses' 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 differs 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 neighborhood houses. The interior, in contrast, as one would expect, feels more personalized by furniture, bric a brac, 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 (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, her hand to shake another's. 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 a lot because of health reasons and so who is but occasionally seen yet still simultaneously seems as present and real as she is mysterious and unknown or, more basic, 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 whom most of us acknowledge on some level; it is to the typical passerby but the life of another stranger whose unique and challenging story the 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 house's walls and the house's plat of land but also further in terms of which area of which room contains the specific life-sustaining machines needed at set times of day. Accordingly, the aural-visual, interactive digital installation poetically represents such an alternative universe and its complexity in ways 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*

One of the first pieces of deviance evidenced in Deshae's house and thus reflected in the installation *Augmented Spirit/Extreme Embodiment* is the neutral-toned carpet and the traces left on it by her wheel chair. 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 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 always 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 whose working sounds deliberately interrupt their 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 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 the space in terms of sound and imagery because the mapping is a subjective

and limiting activity itself. Although Deshae and Katerie discuss the nature of and the product of the collaboration, the process of distillation and creation requires Katerie as an artist to make choices on which situations to represent and how to represent these situations that are not her own. In a sense, the collaboration almost doubly functions as post-modern art (as a relational art work), 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 this process and the artists reflect on that process. All the while Katerie and Deshae invite the audience to observe this process of negotiations and explorations in hopes that the audience in turn will negotiate and explore for themselves in meaningful ways the installation and the ideas it represents, challenges, and celebrates.

*Respiratory treatment 3 of 4*

Indeed, the process of collaboration highly informs the nature of the audience's interaction with the piece. The installation itself whenever displayed 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 in a way that allows the participant to physically "feel" to some small but measurable degree the bodily inconvenience and mental irritation of disability during their processes of creating a sound-scape unique to their movements as well as encounter the sound-scape 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 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. So the installation 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 co-existent realities of the vent user's situation dominates the visual and aural and interpersonal landscapes.

*Food and drink; teeth flossed & brushed; oral medications*

### ***Movement in the Piece***

The sonic installation itself maps and documents the interior space of a mechanical ventilator-dependent person's home. Through the use of audio and video emerges an interactive piece using the sounds that characterize Deshae's daily life. The machines necessary to sustain her life (ventilator, suction canister, oxygen concentrator, wheelchair, chest vest, in-exsufflator, nebulizer) whoosh, whirl, alarm, drone, buzz, blink, vibrate, and tone around her, creating interfaces of tubes and devices as well as cacophony. Interdependency with machines, people, and systems add texture to the song while Deshae's voice carries the melody that, faint though it is, vibrantly arises amidst and because of the interfaces. In this installation viewers 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.

*Respiratory treatment 4 of 4*

The motion of the participant triggers sounds, voices, and noises that are 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) as well as 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) serves to convey gently and in a small way the inconvenience of

disability and at the same time to 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. With both the smaller and larger installation, those who interact with the carpet become part of an electronic instrument where movement encourages the audience to experiment with sound and also, potentially, to realize an alternative perspective on disability. Additionally, a video playing on a portable DVD player illustrates the minutia of Deshae’s various therapies and makes them into their own landscapes. As a whole this project demonstrates how human consciousness, sustained by medical interfaces, emerges to create interesting, unique, and meaningful connections with others and the environment.

**Photo 1: Abstracted Landscape Video of Deshae's Body Undergoing Physical Therapy**



*Vent moved from beside toilet to bed-side*

**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. Additionally, the apparatus is in full view of the audience, and the juxtaposition of the represented medical 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 the environments of other people in her situation who live at home.

*Detachment from chair vent; transfer body, chair to bed*

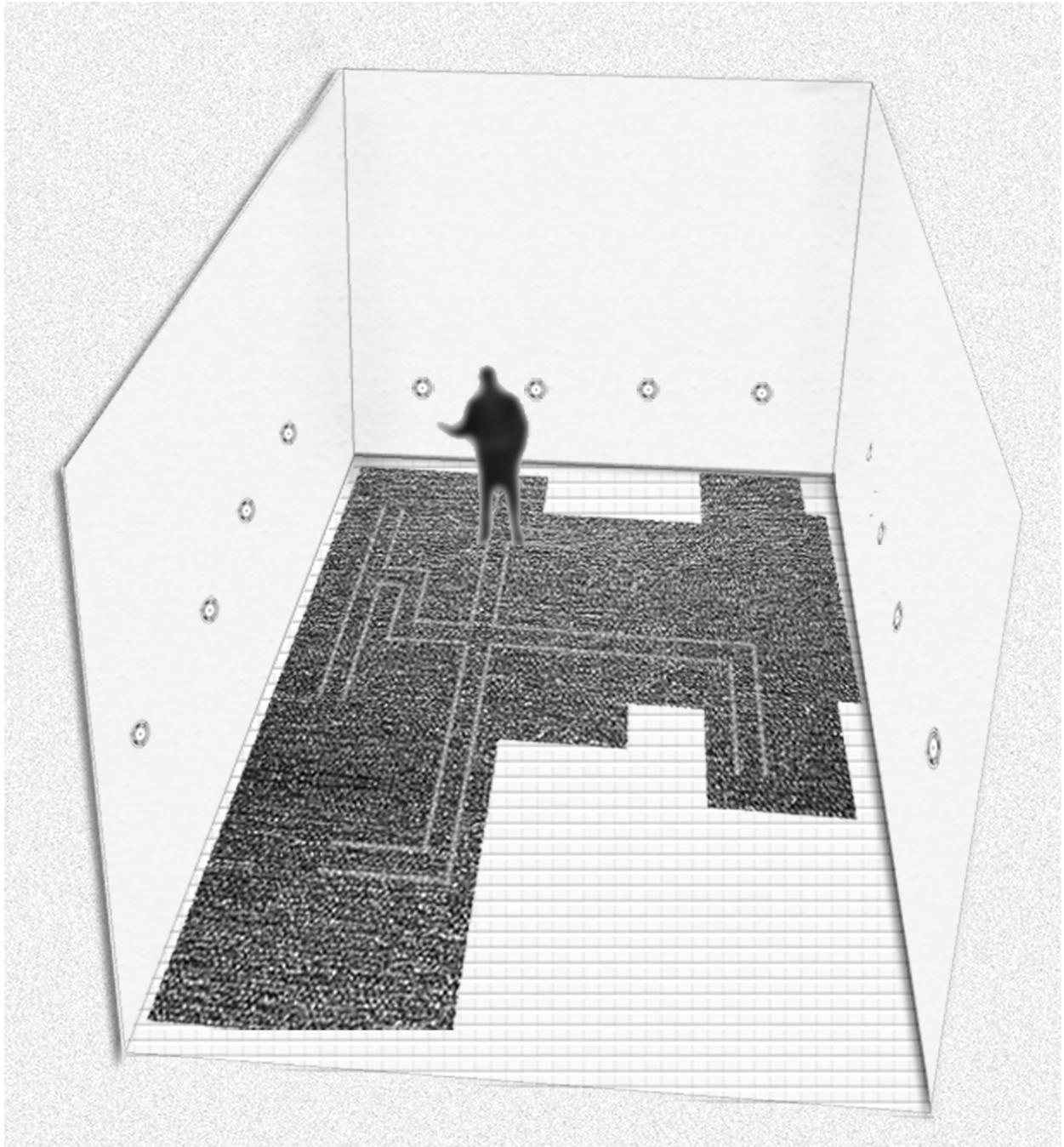
Contingent upon the space allotted to the installation, the audience's bodies (fingers, hands, feet, wheels of other wheelchair users' chairs) come into contact with either or both tracks on the carpet, thereby triggering sets of sounds typical of Deshae's aural experience in a particular room in her house. The participants navigate the space by simultaneously tracing with fingers or walking/shuffling their feet on the two paths, applying pressure. (See Diagram 1: *Participant on Mapped Path*). Different points on the path elicit different sounds or layerings of sound. Surrounding the carpet are sets of wall speakers that broadcast the various mechanical and human sounds (The latter sounds may be familiar ones like conversations or unfamiliar ones like 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 such as living rooms play video that, on first glance, appears to be an abstracted landscape but that, upon closer examination, is the landscape of Deshae's body undergoing some of her daily therapies; in particular, the images capture aspects of Deshae undergoing her physical therapy or passive range of motion with the help of her husband.

*Attachment to bedside vent; Deshae voids via a urinal*

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.

*Wheelchair & vent batteries plugged into their chargers*

**Diagram 1: Participant on Mapped Path**



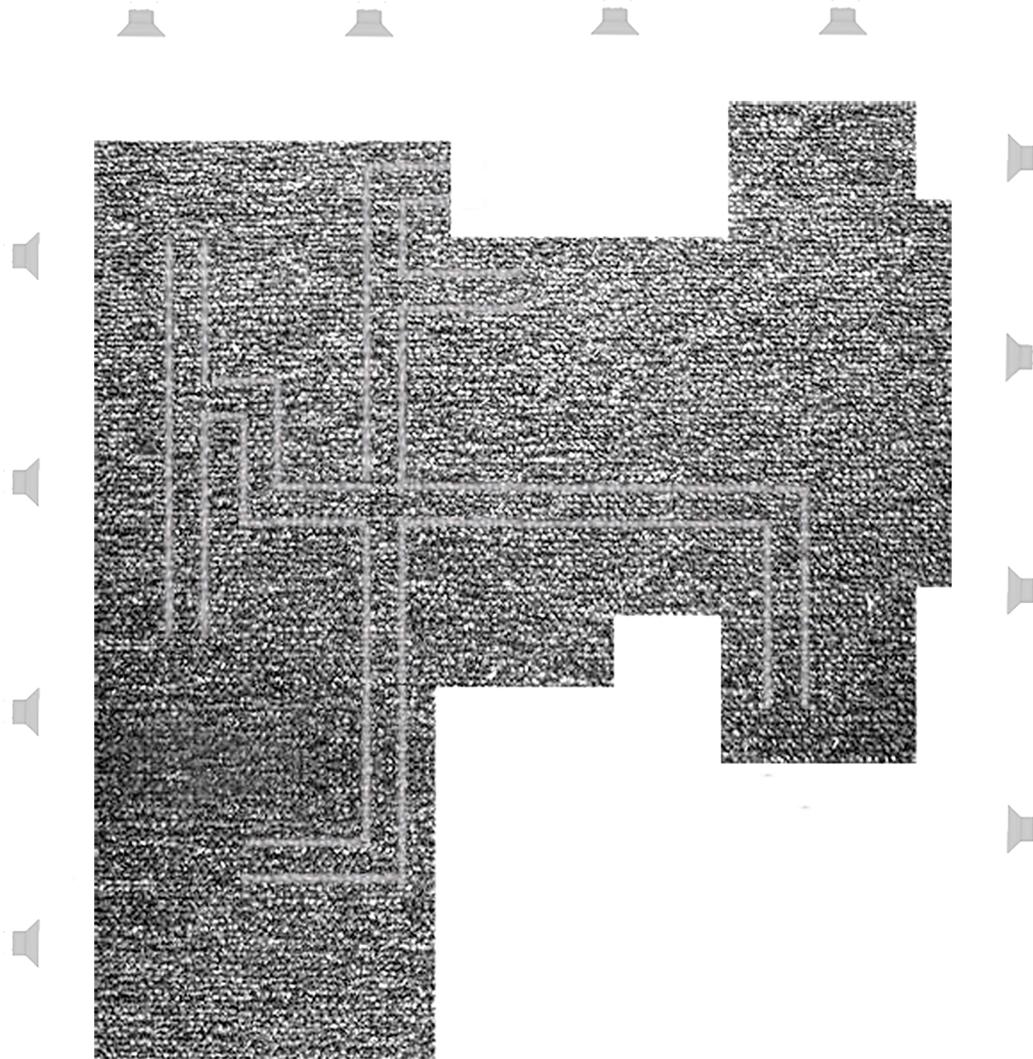
***Size and Scope***

This piece as it appears in museums and similar fora is an installation where people walk or “wheel” the paths. This installation is site-specific, so its size and scope typically depends on

the location specifics wherever the piece appears for public display/co-performance. Ideally there would be a large floor space to lay the carpet and walls for the speakers. (See Diagram 2: *View from Above*.) The area would allow both foot traffic as well as 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.

*Rotating mattress overlay & oxygen concentrator turned on*

**Diagram 2: View from Above**



### ***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

### Photo 2

#### Detail: Hand Touching Stitches

#### *Augmented Spirit/Extreme Embodiment*

#### Sonic Sculpture Mapping the Interior Space of a Vent User



**Sculpture Full View**  
*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 upon a viewer-participant's touch 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 pieces, an audience can engage with this piece by reading the tag with its brief description of the piece, artists' names, and the related artist's websites addresses. However, 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 (for example, 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 upon 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.<sup>2</sup>*

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 recognize and perhaps even develop resonance with the very human aspects present in these, to-them, unfamiliar situations. One of our hopes is that by participating with the installation the audience will experience something akin to what those do 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 on a variety of levels by it (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 with convergences among 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 him or her self 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.<sup>3</sup>*



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## NOTES

<sup>1</sup> For more information about Deshae's health care routine, see [http://www.deshae.org/health\\_care/use.htm](http://www.deshae.org/health_care/use.htm).

<sup>2</sup> Lines excerpted from "The Sick Wife", an unpublished poem by Deshae E. Lott.

<sup>3</sup> Lines excerpted from "The Sick Wife", an unpublished poem by Deshae E. Lott.

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