

Re-Presenting Barriers and Bridges: Practice as Research in a New Dance Project about Ability

by
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Submitted to OCAD University
in partial fulfillment of the requirements for the degree of
Master of Design
in
Inclusive Design

Toronto, Ontario, Canada, September 2013

 Spirit Synott, 2013

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Abstract

This practice-based research project argues that the sharing of personal stories of ability in a world that does not yet meet the needs of people with disabilities, can promote a more inclusive practice of being in the world. As an artist (performer, dancer, visual artist) who uses a manual wheelchair full-time for mobility, I submit this research as a creative praxis exploring the tensions of social inclusion and exclusion. The project overall (in theory and practice) focuses on obstacles and interactions in daily life, and creates layers of auto-ethnographic materials to develop a visceral experience for the audience, intended to create insights by exposing individual and parallel struggles with barriers.

This report offers a discussion and documentation of an original performance (process and 'product') along with a critical analysis of the auto-ethnographic method applied, including a summary of the learning outcomes (personal, political, performative and academic) of the project overall.

**Re-Presenting Barriers and Bridges:
Practice as Research in a New Dance Project about Ability**

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Introduction: Approaching the Barriers



Figure 1. *The Stage is Set.*

This MRP project was motivated by my concern that 'outliers' (or people who differ either physically or in other ways from a perceived norm,) tend to have low visibility in mainstream media. However, it can be argued that we 'outliers' consciously perform important roles in daily life, in many social and workplace settings; therefore we are in fact visible, though often ignored and misrepresented, or under-represented. The MRP is underpinned with this observation about the different levels of visibility and conscious re-presentation that people

with disabilities are given in the media. This project as a whole—both the live performance and the critical report—aim to address this issue and to offer new ways of seeing people with disabilities as active, creative performers.

Preparing for the Performance

The deliberate layering of contrasting text and images as a form of social montage is effective in advertising and is common as a form of expression in our visually oriented world. I argue in these pages that this form of intentional contrast of text and image can be taken further into the realm of performance, where adding a third layer of movement and embodied presence can enliven and strengthen the social message, and may even influence positive social change. We see this multilayered communication montage around us everyday: from the ubiquity of old-fashioned billboards to the 'big screens' and large data ports prevalent today. 3D 'performances' happen around us and to us everyday, even on our laptops, tablets and smart phones. There is advertising everywhere: even on YouTube.

In this research report, I argue that the storytelling function of multimedia advertising applied to these other media can be greatly enhanced and personalized using dance as an additional, live layer of personal interjection of experience, to create a total sense of a fully interactive communication of any message, reaching out to the full

spectrum of the audience's emotions. Added to the compelling layer of live performers interacting in any communication space, the role of dance (with its layer of choreography: the carefully pre-mediated movement of bodies in space) can be seen to communicate most directly and strongly. The choice of spoken stories, text, images, or songs included in any dance performance can trigger the desire to share a response with the moving bodies of the dancers. The deliberate role of the dancer can also cut across the full range of other forms: from the complex and multivalent possible 'meanings' of any simple advertisement to the sophisticated and complex messaging of an interactive media performance. I argue in these pages that the body of the dancer adds a unique layer of meaning to any performative or communicative space, making dance as compelling an interactive format as the tools of social media, or even more.

There is another argument to be made here: this is not only a project about 'process as research' in a generic sense, but specifically about the process of making a mixed-ability dance piece for an audience of people already highly attuned to the nuances of interpretation and of argumentation in a dance choreographed and danced by a woman of different ability. Added to that, this dancer is dancing with meanings in an academic sense as well: pushing at the limits of the predictability of interpretation, whilst engaging head-on with the prejudices and

assumptions we all have in a world where full mobility is still seen as 'the norm'.

In this research report, I aim to show the process that led to my new dance performance about ability, and also to showcase or highlight the issues addressed on a daily basis by a dancer who is also a thinker, who is also an activist on the world stage, pushing for better communication tools and opportunities for communication.

Artistic Objective

My main artistic objective in this project was to create a live performance incorporating contemporary dance, theatre, and digital media.

As elaborated in the discussion section below, I wanted this performance to explore assumptions about relationships between people, things, and the wider environment and look at the inter-relationships and the ways in which they impact upon us all. My drive is to show a lived perspective on ability and limitation that enables viewers to see from a different point of view. I have been involved in many different art forms but dance seems to have the greatest impact on people. It seems to encourage them to not only see that people with disabilities can do more than they might have imagined but also inspire or challenge the audience to try to experiment more with their own, perhaps self-imposed, limitations. I have a professional

background in contemporary dance, fine art, experimental art, martial arts, theatre, film and television. My broad research interests reach cross-cultural communications with and through body movement, where artistic practice transforms into a form of advocacy and activism. I hope to give new insights to you, the reader, and the audiences to come.

The same sets of concerns that have motivated this project, have come to light in many specialist disability publications. The problem, it seems, is not so much a lack of publications by and about artists with disabilities, but rather, the lack of mainstream visibility of these publications that often appear in specialist magazines, in print and online. For instance, a particularly well-articulated discussion was published in a recent article in *Criptomia*, a magazine for wheel chair users, in which a sense of urgency and some underlying anger is helpfully expressed.

In Josie Byzek's notes on *Criptomia*, she puts forward the argument that a more realistic representation would be liberating for audiences as well as for practitioners with disabilities:

I don't like it that media shows only 'inspirational' people. I want people to know what happens when there aren't any accessible parking places left. I want them to know about pressure sore issues—the whole dark side. I don't want their pity. I want them educated. Only then can they understand the need for ADA compliance, rehab availability and me—Karen Miner, C4, Roseville, California medical research. (Byzek)

This reader responds to *Criptopia* by engaging in a highly personalized way to the elaborate discussion about mainstream media as well as to the notion of a eutopia of inclusion, not totally out of the realm of possibility.

Without this sense of reality about the daily, bodily frustrations of living with a disability, we are at risk of misrepresenting ourselves and our experiences.

In relation to the mainstream representation described in the web magazine and blog response above, I argue that we 'outliers' are all vital parts of society and must be visible as such. However, there is a pressing need for new media representations that reflect the diveristy of our society—the dystopic as well as the eutopic. If our roles are to be better understood and appreciated in all the details of daily life, we *need to be heard and seen*. As elaborated below, the desire for a more meaningful representation of diversity in media inspired the approach taken to addressing performance practice as research in this project, and also helped to shape the methodological approach.

The Critical Auto-Ethnographic Framework

This project was developed as an open accessible live event framed with text and video extracts from previous performances. The event was intended to make visible the invisible, since the very lack of

visibility of people with disabilities (especially those of us engaged in physical creative practices) further perpetuates ignorance about people with different abilities. The performance devising process drew upon my prior performances, my readings of relevant social theory, my own writing and reading of poetry, journals, magazines, newspapers, and also my listening to the recordings made by other 'outliers.' In addition, my performance was influenced by the study of other archival materials from events, celebrations, symposia, summits, and scholarly think-tanks, most importantly by the daily streams of consciousness that shape my worldview.

To achieve these aims within the practical dance part of the project, I chose to work in a dance studio tradition, inspired by the scholarly practices associated with the qualitative auto-ethnographic research method, which helped to frame my experiences and self-reflective analysis of my dance practice whilst reaching out to consider the broader political and cultural aspects of my work as well, in order to create or inspire a new understanding of the agency of the dancer with a disability in culture. This combination of practical and theoretical approaches allowed me to express my personal experiences within a critical framework that serves as a lens through which others can see the work differently, which in turn made it less daunting to engage as a performer-scholar in the project as a whole.

The need for such critical lenses in developing practice-as-research has been well expressed by Andrew Sparkes, Professor of social theory and director of the qualitative research unit in the Department of Exercise and Sports Sciences at the University of Exeter, UK. He describes, through an incident, the impact that an auto-ethnographic approach can have in 'real life'. Sparkes' colleague, who initially misunderstood what auto-ethnography could offer, in fact dismissed it as a research tool, was transformed after reading Sparkes' articles. Finally, a student's auto-ethnographic account resonated with the reluctant professor so much as to even change the way he communicated with his own son.

"Auto-ethnography can encourage acts of witnessing, empathy, and connection that extend beyond the self of the author and thereby contribute sociological understanding in ways that, among others, are self-knowing, self-respectful, self-sacrificing, and self-luminous." (Sparkes 222)

My work strives to identify the causes that make it uncomfortable for people 'on the outside' of society to engage actively and creatively in a deliberate visible public setting. In this critical frame, the role of 'complainer' or 'outlier' is replaced by the more positive role of being a first-person witness to injustice. In this way, my 'witnessing' can be reframed and will more likely be interpreted as valid and credible. My

hybrid approach licensed me to introduce different formats that deliberately intersect, overlap, and layer images, movement and ideas, including dance and archival material, in a way that may lend itself to the fast-paced, multi-faceted, multi-platform digital arena.

Defining the Terms: Dancing Ability in a Canadian Context

Many and varied definitions of 'disability arts' have been put forward by government agencies and advisory panels over the years. These provide part of the context against which my dance project is presented.

The Canada Council for the Arts published a much-cited policy paper defining terms in this way:

FOCUS on DISABILITY and DEAF ARTS in CANADA

Disability Arts—a vibrant and richly varied field in which artists with disabilities create work that expresses their identities as disabled people—needs to be contextualized within the larger movements that gave birth to it. We will situate disability arts within the Independent Living (IL) and Human Rights (HR) movements, which include a broad coalition of people with disabilities who have come to boldly—and bodily—challenge prevailing attitudes and stereotypes of disability in media and popular culture. (Jacobson and McMurchy 4)

...

Artists with disability are re-evaluating traditionally held standards of professionalism and artistic merit by creating works that deliver both new images of bodies in motion, at rest and at play, and clearly articulated (or not so clearly, which challenges us to pay attention), compelling performances. Disability often injects live performance with an urgency and power that can never be produced under strictly formal conditions. The stakes for artists with

disability are high, keeping work edgy, visceral and replete with “universal” messages. (ibid 7)

Having read many such definitions and come to the conclusion that none of them adequately contained my own understandings, I experienced a cycle of emotional responses to the definitional materials, leading from a sense of restriction to a feeling of relief and catharsis. Ultimately I decided that the only way to present my own experience was to dance it, from my own point of view, using the material experiences of my own life as the ‘content’ and frame for the work.

Moving Beyond Definitions

It is a basic understanding in activist politics that it is not possible to achieve radical change until the problem is first acknowledged. Part of the early stages of research in any area is to define the problem space. Philosophers claim that solution resides within the problem. Audiences are drawn to drama and to the concept of the great triumph over tragedy. But is disability the tragedy itself, or the lens through which it is portrayed? Some efforts are being made to limiting labeling.¹

My live performance was named *Re-Presenting Barriers and Bridges* to reflect an experiential self-portrait. Six different old TV’s, six chairs, a

¹@LGDavidOnley: Very pleased to host @OCAD for a roundtable discussion about redesigning the International Symbol of Access #deep2013 #inclusion. Twitter.com. 11:30 am, July 13, 2013.

seven foot long table, and one sturdy suitcase are all characters in this multi-media production. My dance partner Perry Augustine and I danced around, on top of, and under the table featuring the equally large word, "Assumptions". This performance addresses many assumptions about relationships between people, things and environment and how those relationships impact us. A variety of carefully chosen words I experience with all my senses played out on a selection of surfaces. On various screens, small, medium and large, using scale as a metaphor for highly visible and less noticed, I ran archival footages from my other noteworthy performances for sharing with this new audience.

Approximately eighteen feet high by twenty-four feet wide directly framing the live performance at Design Enabling Economies & Policies (DEEP) conference, are stills and videos are projected on the big screen behind the performers. Layering the song lyrics and statistics as well as my personal commentary allowed for experimentation with different forms of captioning within that frame. The intention was to assist and include audience members who may learn and understand better with both text and audio. This includes people who are hard of hearing (HOH), deaf and those for whom English is a second language (ESL). We offered live audio description to those with low or no vision. American Sign Language (ASL) and captioning on a separate screen to

the right was remote and onsite, sponsored by the Inclusive Media and Design.

We are not visible in mainstream media. As I noted previously, my performance is a response to my concern about mainstream media's representations of diversity. I will describe some of these influences below, and discuss how these influenced my project.

As a child I was influenced by a movie called A Patch of Blue starring Sidney Poitier. This was a story about two very different cultures learning about each other and the two most unlikely characters even falling in love. It was the first story I saw of a woman with a disability. She was blind but she was blonde and she could have been me. He fell in love with her, which said to me that someone could fall in love with me someday.

Sidney Poitier had a huge influence on my choices in life and in art. American-born Bahamian actor, film director, author, and diplomat, showed that those choices can influence audiences. He writes about his journey from illiterate youngster in the Bahamas to Icon in the Hollywood scene in his books "The Measure of a Man" and "Life Beyond Measure".

Star Trek is another example of different cultures working together. You did not judge a character by their appearance you get to know

them by their interactions and behaviors. Don't you think that device often seen on that sci-fi series resembles our cell phones today?

Somehow we went from "Ironside" to "The Six Million Dollar Man", the series to the movie "Avatar." Raymond Burr played as a paraplegic Chief of detectives for almost a decade from the mid 60's to the mid 1970's in the series and movie "Ironside". They even show his modified van; yet another device for me to aspire to get for my independence.

According to Wikipedia, "The show enjoyed an eight-season run on NBC, drawing respectable, if not always high, ratings." That was, and is, how shows earn their continued presence. His character had a job, was respected and smart. The story wasn't about his disability. Global TV plans to re-imagine a new Ironside, once again choosing an actor without a disability ("Blair Underwood Returns As Re-Imagined 'Ironside'.")

As for "The Six Million Dollar Man" and "Bionic Woman," I am all for advances in assistive devices helping us to be the best that we can be. However, my problem with this is that it says to the audience people with disabilities have to be superhuman to be accepted.

Fast forward to Glee where a non-disabled actor once again portrays a choir singing dancer geeky guy stereotype to whom they give the

worst choreography, except in his dream sequences where he can walk and dance again, and "Covert Affairs" where a sighted guy plays a blind guy. As for "Avatar" - Would people who use wheelchairs preferred to live in a fantasyland just so they could walk? Despite shows like, "Switched at Birth", "Coronation Street" and "Pushgirls" and Torontos' own, "Degrassi 5," I have noticed a decline in stories including people with disabilities.

Tobias Forrest a Los Angeles-based actor who used a wheel chair because of spinal cord injury and spent several months in Pittsburgh in 2006 as the lead in a City Theatre production said, "But the big problem is about opportunity. If all the chances to play characters with disabilities—or characters without disabilities—are given to non-disabled actors, we lose an opportunity to move forward in our careers."

"Hollywood's practice of casting big names in the roles of characters with disabilities produces a "Catch-22," notes reporter Greg Gilman, who covered the protestations about the "Ironside" casting in the The Wrap, an entertainment industry publication. "There won't be any disabled stars until disabled actors are given prominent roles," he wrote.

Is society as a whole afraid of disability? Or are able-bodied people who have not had to engage with disability in their lives, ignorant by virtue of their unfamiliarity? If so, how is that possible? We people with disabilities are everywhere (almost), and so are the walkers and wheelchairs we sometimes use. However, the portrayal of disability in mainstream film and television is still minimal at best, and often not portrayed by actors with disabilities even when scripts include characters with disabilities. All too often, disability is 'cured' miraculously, for instance on soap operas such as 'The Young and the Restless'. Characters on that particular television soap have suddenly gone blind and deaf and become quadriplegic, yet unlike in real life, all those characters so tragically afflicted were then 'healed' (apart from the one character named Hope, ironically enough). There is a serious point here. Even if soaps are typically involved with unrealistic or outrageous escape drama scenarios, still there is a real world danger to these specific instances of 'normalizing disability' by erasing or 'healing' it. Truth is indeed stranger than fiction.

The Internet shares a more equal set of images, many posted by people with disabilities themselves. There, on the Internet, it is possible to find amazing and true stories such as that of Sue Austin, whose account of her own adventures amazed millions of viewers

when shared on TED Talks (“Sue Austin: Deep sea diving ... in a wheelchair”), also captured by the popular press more recently in the *National Enquirer* magazine’s feature (“Wheely Beautiful, Handicapped Woman Makes Waves Performing Underwater Ballet.”)

These features in mass media outlets pose a problem: while on the one hand it is refreshing to see people with disabilities at all, there is still the risk that the framing of the stories alongside those of ‘normal people’ sends a message that somehow people who use assistive devices such as wheelchairs are ‘freaks’. Yet there is a more positive aspect to this representation too. On the TED Talks series, Sue Austin explains that she has received similar reactions from audiences to those I have received in response to my own dance work: surprise, shock, support, and a mixture of emotions which are at once heartening and disturbing in the sense of the ‘jarring’ with the ‘norm’ which they emphasize.



Figure 2. *Wheely Beautiful*.

Image Source: National Enquirer

http://www.ted.com/talks/sue_austin_deep_sea_diving_in_a_wheelchair.html.

The YouTube Channel and the TED Talks series in particular can be seen as some of the most inclusive and far-reaching mainstream mediated spaces where most interesting, international stories are posted today. However, not everyone has access to the Internet. Nor can all of us can afford to have an underwater breathing apparatus and scuba diving wheelchair. Access is still limited. . .

It is useful and informative to compare some of the responses Sue Austin records having, to some of those I have had to my own work, in that we seem to share this sense of yourself being defined by others' ideas about the wheelchair rather than about the creative person. In November 2012, Austin said: "They seem to see me in terms of their

assumptions of what it must be like to be in a wheelchair.” I, too, am working to transform and inform. The associations attached to dance are similar to that of scuba diving—freedom, grace physical ability.

In a letter received from Catherine Frazee after she attended one of my dance shows, she wrote that my performance not only changed the way the students saw disability, but how they felt about disability as well. Sue Austin is making the same kind of impact with her art.



Figure 3. *Perfect Balance*.

Image Source: National Inquire
http://www.ted.com/talks/sue_austin_deep_sea_diving_in_a_wheelchair.html.

In the National Inquirer the text reads, “PERFECT BALANCE: Sue Austin performs her amazing movements in a summer dress, her arms moving fluidly among the sea life.” She can scuba dive without the

wheelchair but she decided to combine the thrill of diving with the idea of restriction of the wheelchair. She doesn't need her wheelchair to do a scuba ballet. Sue purposely wanted to include her wheelchair to change the way it is seen and imposed on those of us who use it for mobility.

Developing the Performance: an Iterative Process of Research-into-Practice

My process when working on a new project is iterative; preferably, in a dance studio with mirrors—to discover shapes, movement, technical needs, and transitions that convey the ideas being developed. Many hours, months, or years can go into developing a satisfying result. This is because a wide variety of attempts are required in order to find the desired combination of music and movement. The development of a gestural dance vocabulary is recorded on video for many reasons. Only some of that vocabulary is used in the final production. Playing it back and viewing it is an opportunity to make choices about what my experience has shown me that the audience will experience. It is important to keep the archived material to use at a later date for further development. In the process of doing, viewing, studying, listening, linking, and analyzing each iteration, I journal my thoughts and sketches to clarify ideas. This is a solitary process. When and where possible, dancers, choreographers, and dramaturges are invited

to join in conversation to distill and tease out these ideas. I prefer to work with other dancers, duet and ensemble, rather than solo because we can do more, convey more when someone can lift me and with chosen set pieces and props.

Sitting at the core of my research is my performance piece, where conceptualizing and creating the environment was as important as choreographing the dance. Setting the physicality of the piece was the first challenge. I began by playing with the choreography of a set of different kinds of chairs—some on wheels, some not—because people look differently at a wheelchair than they do other chairs, even other chairs with wheels (Figure 4.)



Figure 4. *Six Chairs With and Without Wheels.*

In an educational and or conference setting using historical reference by use of vintage TV's (Figure 5) and strategic choices of significant work, I have achieved laying my foundation as a dancer and choreographer in mainstream and disability arts, from conferences and throughout well recognized dance venues and festivals. Many people who use wheelchairs either manual or motorized often stay in their assistive device no matter the setting. I introduced the idea of choice or preference by transferring from one wheeled chair to another. Demonstrating complexity of relationships, together and separately,

my dance partner Perry Augustine and I move from one surface to another to show fear, indifference, difficulty and grace.



Figure 5. *Tower of TV Screens.*

'Being present at the table' is a metaphor for inclusion in the seats of power. I decided to use this metaphor in the dance piece, as one of the key messages I wanted audiences to take away was that the only way to change attitudes, policies, laws, educational policies and

practices, and to remove or lesson the cultural levels of ignorance, fear and denial, is to be present, at the table: to re-frame and re-view that which we as a society don't want to see. The dance piece focuses on the act of sitting at the table and then reaching out as a powerful and dangerous extension: to reach out might attract attention but might also result in rejection.

Performance Analysis: Using the Materials of Life

Physical description

Don't explain, a song by Beth Hart, begins *Re-Presenting Barriers and Bridges*. The set is composed of a table, which is configured to look as if it is in a conference or school setting. The words on the back of the red and white chairs are DENIAL, FEAR and IGNORANCE.

Perry Augustine, my dance partner, sits in the FEAR chair. He watches the stills float up on the big screen of some of the unsanitary parking passageways and parking spots piled with garbage. This includes my replacement spot during reconstruction in the parking garage. In these areas where I must travel, the walls still leak and puddle adjacent and under my vehicle. However, this is not the case in the areas of the other tenants' passageways.



Figure 6. *Visible denial.*

In the dance piece, I transfer from my wheelchair to the office chair on the right, labeled Vital. We look at the images. I transfer closer to him by sitting in the IGNORANCE labeled chair. He doesn't want me to sit beside him, so he moves to the DENIAL labeled chair. I move toward him again. Then I reach down to the leg of the IGNORANCE chair to put the ignorance down. As I chase him, he moves, and so forth. I put down the DENIAL chair eventually. Perry picks all three chairs up at once and removes them.

Perry dances confined under the table as the second song by Justin Hines, *How We Fly* introduces the idea of struggle and support. I dance restlessly on top of the table. The suitcase Perry clings to represents more obstacles to be dealt with. Perry pushes it out from under the table. As I look down, I find Perry looking up and reaching up. Our hands embrace and we push, pull and release.



Figure 7. *Push, Pull, Release.*

Perry comes out from under the table, behind me. We echo each other's movements without facing each other to represent similar parallels of life experience. He reaches out and touches me to show he supports me. He lifts me from the table, spins me around as if we are flying together. We fly, reaching out in together, then apart. Now each

on either side of the table, we turn the table with the huge word "Assumptions" over upside down onto the suitcase, making the table a barrier, a ramp, a bridge. While I bang my chair up against it to figure out how to deal with these daily obstructions Justin Hines sings *When the Morning Comes*. The projected images have now changed to sunrises and ramps beside the stairs proving it is possible to have both. We use a heavy duty suitcase representing baggage, which we all have. Under the table, the suitcase becomes the foundation of another potential obstacle. Then as a building block, I struggle to wheel over the table. I balance on the table and the suitcase. Precarious, unsteady and difficult as life can be, we need to take risks to find solutions and find balance. I balance in the middle and wheel off the other side. Turn around and do it again because life with a disability in an inaccessible society is filled with a lot of repetition.



Figure 8. *Struggle and Balance*.

Perry dances along side me but is almost oblivious to my struggle—as he represents society, lost in their own dance, be it social media, texting, what have you, unaware of the struggles of those around them—while I struggle with the table as barrier ramp and bridge. Then we recognize something in each other again and work together to put Assumptions on its head. On either side of the set, there are two piles of old TVs in a stack of three—large, medium and small—all playing significant dance performances. The significant pieces include milestone festivals and pieces from my performances set at

conferences, because this piece was performed at the Design Enabling Economies & Policies² (DEEP), an international conference hosted by OCAD University³ (OCADU), Inclusive Design Institute⁴ (IDI) and Inclusive Design Research Centre⁵ (IDRC).

Background videos

There is a duet segment from a larger piece from SummerWorks Theatre Festival, May Works, Access International: The fringe Festival of Independent Dance Artists (fFIDA)⁶. Interestingly, the location was moved last minute and I had to buy a Marley dance floor in order to do the performance, as the new space was carpeted. There are stories for all of them but these will be reserved for future projects. However, I will show some evidence of influence through dance from a human rights conference for the United Steel Workers Union (USW) because I have a story to share of the effect that performance had on the audience. Dusk Dances must be shared in the writing somewhere for its inclusion of audience from all ages and walks of life. My foundations and growth play out in these simultaneously looped videos. They are not just old work DVD-Rs digitized from Hi8 analogue video archives. They represent many parts of shaping vocabulary as a dancer, as a choreographer, as storyteller. They are as much a part of me, my

² <http://deep.idrc.ocadu.ca/>

³ <http://www.ocadu.ca/>

⁴ <http://inclusivedesign.ca/>

⁵ <http://idrc.ocadu.ca/>

⁶ There is a fairly early conference called Access International.

practice, my politics, my activism, my prayers and my pitch, to provoke, promote and propagate change as any other form of expression. This re-presentation of dance work is to prevent them from being left behind. Maybe they are too small, too far from the clear view of the audience. This is because they are becoming distant to me as well. "You are only as good as your latest work" seems to be the historical and current trend in the film, television and theatre, and new media heightens statements of this nature. Unless the digital landscape gets easier, more affordable, I am not the only one being left behind. I will have no say or control of how my image is used or displayed if I don't understand how the tools work.

Statistics and relevant quotations were projected on a big screen, center stage: notes on disability and thoughts for the audience to ponder. I built the table with a bit of help from my artist friend Jungle Ling and the metal shop at OCAD U because the IKEA legs I bought broke their spot weld after about four rehearsals: thankfully not while I was on the table.

Coming back to the performance, Perry and I take turns moving obstacles and pushing away or putting down our individual baggage. Then we find ways to support each other as we dance together to another Beth Hart song, *I'll Take Care of You*. We return back to our roots as if dancing in the nightclubs not entangled but recognizing

each other's personalities, egging each other on and in the end embracing in joy and solidarity of acceptance of difference.

I have to admit I have difficulty reading, so I love words when they paint pictures. I discovered I am not naturally an academic wordsmith.

A variety of carefully chosen words, I experience with all my senses, played out on a selection of surfaces. I used hand-painted, hand-written with marker and noteworthy type on those different surfaces motivated by commercial advertising and my emotional response to those words.

Process description

I see and feel patterns and rhythms in everything. At first I wanted to use boxes to illustrate the common phrase "think outside of the box." I wanted to play with the concept of inside/outside. We don't always show what we feel. I also have a thing for circles and squares and figure eights. I used photos of patterns in wave of water patterns in shadows, bark cracks and trees, condensation rolling down the window, frozen water clinging to the grid of a pigeon net looks like glass dancers or gymnasts. Everything looks like dance to me. The way we walk. The way we see and don't see each other. The way traffic moves whether that pedestrians or vehicle.

I have a general idea of what I'm going for. Constriction release. I wanted to metaphorically and literally play with the big picture and the little picture. I wanted this piece to be comforting at times and uncomfortable at times. I wanted to show some of the obstacles that I deal with on a daily basis that are physical, attitudinal and systemic. Steps, even one can be an issue. Ramps are not always available. Ramps can be too steep. And yet I wanted to show movement in time and space with discomfort and with grace.

Rehearsals took place in a few different places. Sometimes we worked in my apartment. We moved furniture out of the way so that we could find certain moves, certain shapes that have worked before. I had it in my head that I wanted a cello piece and found a cello player who had MS but in the end that piece didn't work out. Jacqueline Du Pre from a CD called 'Great recordings of the century - Edward Elgar.' Part of me wanted to return to the notion of using Canadian music so I poured through some Jeff Healey who had a big influence on my early days of dancing in night clubs doing wheelies. I looked at more current Canadian artists like Justin Hines. Other contemporary artists I was using for warm-ups seem to target both Perry and myself. Beth Hart and Joe Bonamassa in their CD Don't Explain featuring some great rhythm and blues from the likes of Billy Holiday and Etta James. I would change up the order of the songs to accommodate the choices

regarding the movement of the table, the chairs and the suitcase, which originally was a block of wood. I wanted to use something rounded like the trunk of a tree but halved and it would be that fulcrum under the table that I would balance on with my wheelchair so that my wheel would echo the tree trunk underneath the table, again mirroring or echoing circles. I couldn't find a rounded object large enough to do what I had in mind. But I found a block of wood that was like a railroad tie that served as my fulcrum for the meantime. But it could not explain or justify that choice other than it was a block of wood that represented obstacle and foundation building block. But later I thought to bring in a sturdy Samsonite suitcase. The suitcase was given to me for my trip to Italy to study in the Florence program when I was a student at OCA many years ago I still have it. The suitcase in the performance represents baggage; we all have it.

Perry and I greeted each other. We shared our updates with each other as we listened to one another, moving, stretching and recalling our days. We experimented with a variety of music to reflect a variety of moods, words, movements and sounds that resonated with confinement, freedom, baggage—lost and found.

At first, I knew that I wanted to use the table as multi-purpose prop. The table is a tool for discussion. I thought of using the table as a barrier. My dance partner would come out with three stacked chairs

and arrange them in a way that would block my passage I would stack the chairs to clear my passage. Not knowing who would set them up as a roadblock for me. I was going to use strategically placed books to indicate education. This dancer would not see me nor I them until we did a few rotations of this repetitive dance. Increasingly, I become less and less tolerant but the exercise was too literal and tiring and taxing on my back and shoulders. Finding chairs light enough for the task of many rehearsal was also a challenge. Another previous dance partner and I explored in the National Ballet School and recorded playing with chairs. We had chairs beside each other, facing in the same direction facing back to back. Three chairs, my chair added together to make four. You don't see my wheelchair right away. My dance partner and I appear to be waiting and waiting and impatient and end up playing a bit of musical chairs. I was looking for armless but they were all too heavy. I wanted the color scheme to be black and white because things aren't black and white in life. I introduced red as an emotional component. Red and white represent simple patriotism, innocence, love or hate and our lifeblood. As I worked on the videos, I brought them into the studio space where I had the set up. The equipment included various sized television sets, DVD players, adaptors on top of DVD players. I chose work that illustrated different settings and challenges, some with ramps some without. Settings included

conferences, included an International Access conference a human rights conference, mainstream, accessible and inaccessible.

I knew from the beginning that I wanted to turn the table into a step converted into a precarious ramp. We tried various iterations of the table, trying different things until we were left with the best parts for the development of the story. We had to work out the order that I wanted the table to be positioned which lead to the development transitions. Deciding what shapes. Controlled improve at first with emotional intentions and movement in mind. Trial and error, trust, intuitions, forward movement, backward movement. Deciding when we interacted with each other and when we would not. The chase. The echoing motions indicating we have parallel experiences. Working together on lifts and weight sharing supporting each other.

Perry and I started each rehearsal with stretching, music and conversation. We stretched together. We stretched apart. We would talk, move and listen and watch. I talked a lot about what I wanted certain sections to feel like.

I wanted to do inside outside the box because I think that there are times in each of our lives when we feel included or not included. You can see it but you can't use it or you can't reach it. Something about repetition. Everywhere and in everything inspires certain sounds.

My methodology when working on a new project, smooth even uncarpeted studio, preferably in a dance studio with mirrors to discover shapes, movement, technical requirements and transitions that convey the ideas being worked on. There are many hours, months, even years that can go into developing a satisfying result and a wide variety of attempts to find just the right look and feel, music and movement.

I am drawn to multiple forms of storytelling as an observer of behavior of animals, humans, nature, senses, things and their many intersections and relationships. As communication tools and styles change and develop, my curiosity to engage and adapt my own understanding of inclusion and exclusion grows.

Art that engages us takes us on a journey. We all have experienced comfort or relief from art that engages us and then we want to share that. The activist in me wants that ripple effect. All forms of art making are devices for story telling but it is not always comfortable. It can however, be a relief, cathartic, cleansing, awakening to name a few responses. My focus is on cross-cultural communication. What do I mean by this? Some believe that disability is a culture. But it is not a self-contained unit. There are as many sub-sets or imagined hierarchies as there are in racial definitions.

"...I would consider disability on par with the oppression of people of

color. Indeed, one famous disabilities studies scholar who taught at a historically black college was denied tenure (subsequently reversed) for having made the analogy between race and disability." (Davis)

To illustrate one size doesn't fit all, I asked at a creative casting symposium how an actor with a disability can get noticed and get work. Tanya Lee Williams responded with something to the effect of "whenever there is an industry awards ceremony a bunch of my friends and we buy a table and make our presence known." Well, there is a big difference between the perception of a table of actors who are of color and a table of actors who have disabilities. They would be perceived as colleagues privileged enough to afford to be there and we must have been had a table donated to let us out of our living facility by some organization that helps shut-ins get out. Cross-cultural pollination in my work is the intention behind most of my choices in art making, conference participation, education and other forms of communication. If we listen and engage in the struggles and successes of other cultures and how they dealt with them, then, perhaps we learn more about them and ourselves.

Some of us have had the benefit of nurturing and tools for all kinds of communication. Some of us have been discouraged and denied what others take for granted. So I am asking that we all be more mindful and open in every setting we find ourselves.

You may not see it, feel it or know it until it happens to you or someone you love. When your body starts to deteriorate it is not only physically draining, it is emotionally weakening. When our mind doesn't work like it once did, that is immobilizing. Experiencing both lately gives me some insight into other disabilities, and into the human condition. Sure, we all have strengths and weaknesses. But who has access to resources to function at their best? What are those resources? Who decides who gets those resources? How many layers are there to receiving those resources? Art can promote a better understanding that inclusion and access can engender better functionality for society.

I have always been stared at. I am approached by strangers, questioning what I did to myself to end up in a wheelchair; or stating what a shame I am so beautiful and wheelchair-bound. I am neither heading toward nor tied to my wheelchair. As a choreographer, performer and storyteller I can be spectacular rather than a spectacle. I can impact rather than just react. I participate and/or perform in many conference settings to get people talking. The auto-ethnography and use of a variety of styles of writing within this document and performance are tools to serve as a metaphor and reflection of inclusive design being the essence of the many ways we can and do survive to thrive.

My process/practice differs from other dance artists who use wheelchairs. I choose to work in a very specific way with my chair. I explore it. I dance in it, under it on top of it, in common and uncommon positions. My website, www.spiritsinit.com, offers examples. To position my work, the following offers cultural, historical context, illustrating difference of practice, highlighting the use of wheelchairs in dance.

For the last two years AXIS Dance has appeared on the currently very popular American program *So You Think You Can Dance* and been fully financially functioning in the United States for over 20 years (AXIS Dance Company.) A friend visiting India cut out a newspaper article about Indian Sufi dancers who used manual wheelchairs. So I looked them up on the Internet and found them on YouTube ("Disabled Sufi dancers put up a show on wheelchairs.") They, and many other mixed ability dancers, don't get out of their wheelchairs. Sometimes they disguise them. I may choose in some choreography to reveal my wheelchair later in the performance so the audience sees the person first. But I dance, in, on, under my wheelchair to change people's fearful perception of it being the beginning of the end. A wheelchair enables possibility. Negative perception disables.

Having a physical disability is not the punctuating trauma in my life. It certainly highlights a lot of things. But it's not the only thing that

makes me who I am and how I react to things. That equation comes from so much more.

The last two years of my life have been challenging on many levels simultaneously: technically, academically, physically and emotionally. The pressure and difficulties are not just driven by this Inclusive Design MDes (Master of Design) program, but by larger life management in a society full of systemic barriers. I learned it is really outrageous to ask for those who purport to provide assistance to be as transparent as we who need assistance. Society and the decision makers say they didn't know, when faced with dissatisfaction of it's minority's' concerns of injustice and Band-Aid solutions for structural shortfalls. I can't possibly analyze all the bureaucracy out there. Paul K. Longmore, professor of History at San Francisco State University, has documented essay after essay of abuse in his book *Why I burned my Book and Other Essays on Disability*.

I am one individual, but being treated "less than" results in feelings that need to be expressed. Dance with a dash of multi media has been my preferred language for a number of years when words just further limited me.

I learned that captioning has a long way to go to before it will be a useful and inclusive source for translation tools. I chose to work with captioning as part of my practice and research because it is all about

communicating clearly to the fullest. Current practices of caption display distract the audience from the performance and are also replete with “inaudible” moments. This could be reduced by finding captioners adept at understanding the speech patterns or accent of the speakers from almost any country in the world.

I learned that there are different video editing possibilities, software, apps, programs, with some similar features—some easier for people like me and some only for those with a great deal of understanding of technology. I experimented with iMovie, Final Cut, Premier and they all work slightly differently and require a lot of experimentation and training. I learned that any one of them can’t just be chosen in the expectation that it can do everything as advertised. It is not as easy as the developers would have consumers believe, and even the experts argue about which software is better. Who can afford to buy them all and try them all and/or afford to pay someone to do the work for them and/or train them? I learned in both Final Cut and iMovie instructions to lay down the sound first then the images and video clips and more often than not many dance pieces work just as well with completely different music.

Using the large screened images and video clips with some variety of effects and lyric captioning along with commentary was successful in some ways and not in others. I personally liked the large background

as a backdrop. I liked my iMovie captioning as it is much larger, and in conference settings the larger the better not only for the audience but for documenting video recording for remote viewers and a more complete documentation of the work.

Discussion

One common factor of all the many festivals and conferences I attend is their focus on the human need to be heard and seen, witnessed and accounted for. Similarly, a common 'lack' in the public sphere overall- in the educational system, the legal system, film and television, the arts in general, union representation and other elected representative bodies-is a visible stakeholder community representing the full spectrum of people of our diverse world. If all sectors of society, including the academic sector, could unite in an effort to advocate for the "other" not only as a research subject but also as active agents of their own representation.

Sharing our experiences and stories as active agents will not only liberate our own voices; it will also help society to look at things in a more holistic way.

I learned to keep asking for help because one never knows where help might be found. I talked to many different people in different departments at OCADU in the process of this research, as I needed help learning to digitize my analogue video footage; in that regard I made a new alliance with the Social Media and Communications Lab (SMAC Lab). I met Judith Doyle at a Disrupting and Undoing event, where we were both exhibiting our work. We discussed working together on her project 'Pathways' and my 'Re-Presenting Barriers and

Bridges', neither of us knowing what a collaboration might look or feel like, but knowing that something useful and productive would be manifest in the intersection of our ideas.

In conversation as part of the research process, I became aware that when I am successful at creating something that moves people, perhaps even evokes discussion and or drives change I feel some relief. Why? I cannot help but be disturbed by what is still a large part of our social storytelling modes, film and television because of its lack of real people with real disabilities.

I wanted to address ideas on access, barriers and bridges, in a way the audience was unfamiliar with to provoke a visceral response. Based on the feedback I received from the audience, I created awareness and a different perspective with retrospective and current influences to engage and perhaps disrupt the viewing audience there would be a relief of the words projected large on the big screen for some and a distraction for others. That worked for me because when I have difficulty understanding something, I get uncomfortable, overwhelmed, and my attention gets conflicted. Multi modal means of information receiving choice is helpful to me. I would like to continue to experiment with different modes of captioning the lyrics and injecting my thoughts and experiences with mainstream tools and assistive technology. I would like to collect responses from

the audience in a variety of methods to follow-up additional data research feedback from the audience of my performances.

Designing tools, constructing and collecting such data is not easy. Some people need time to process what they saw others want to engage in question and answer period immediately. I would like to look at cross-cultural communication tools to continue my own development. I find that when reading captions or subtitles they are often too fast for me to process. I am sure that I am not alone in this. Continuing to explore captions would be helpful for others. Related to this, I'd like to do more in exploration of performance audio description. I asked several students to be available to describe my work for audience members of low or no vision, knowing that as individuals, they will have different styles. It would be interesting to collaborate with others on exploring that subject for this reason. It is evident to me that there is no limit to what can be explored. It is my intention to include others in my art making process and not just make art and leave it for someone else to translate. Ambitious, unrealistic or naïve but there is no one-size-fits-all. I do not accept the status quo. We need to keep trying. We need to keep refining. We need to keep finding better ways to communicate our stories. The Web serial *MyGimplyLife* ("My Gimpy Life") resembles my collaborative video *Audition* with ACTRA Toronto ("The Audition.")

There were problems with the timing and the choice of images. When I tried to make edits I ran in to issues I didn't have the knowledge or the resources or time to solve. I would like to experiment more with different software like iMovie, Final Cut and Premiere. They all have different things to offer and I am not sure which is the best one for me to choose. I know the same thing happens with learning tools and assistive devices. I would like to rework the images and timing videos to be what I wanted them to be not just what I was able to accomplish in a given amount of time.

Conclusion

We are and can be vital part of the fabric of society. Look at our own honorable David C. Onley lieutenant Governor of Ontario, who represents Her Majesty the Queen Elizabeth II as Queen of Canada and head of state. He was one of the first persons with a visible disability. He started his career on radio then made his way to breakfast television then worked his way to becoming an anchorman on CP24.

I was a regular as a model in print ads as well as live Television on the Shopping Channel for many years but never made enough to make a living. I have been performing dance for 15 years professionally and don't make at living at that either. I have acted in commercials, in film and in television. Yet, when mainstream advertising perpetuates fear of wheelchairs with images at bus shelters, as the next image will show, how am I or any other actor who uses a wheelchair supposed to get work? The Headline in Figure 9 reads "Wouldn't you want to know at 30 that you'll need this at 50?" over an empty manual wheelchair.



Figure 9. Advertisement over an empty manual wheel chair.

So I joined the acting union for film and television. I critiqued the mainstream depictions and representations. I got involved in the diversity committee, ran for council was appointed to the ACTRA Toronto board. I alternate on the ACTRA National council. I've spoken with industry leaders, producers, developers, writers directors and casting agents, who all, at one time or another have said something to the effect of "why should it matter to us?" or my only audience is other people with disabilities. Curb cuts show why inclusion should matter. They benefit more than those they were designed for. When I perform I'm not only inspiring those with disabilities but I'm also encouraging possibilities the audience hadn't thought of before.

ACTRA and I created a humorous look at inaccessibility in general with the lens on casting agencies as an awareness tool ("The Audition.") I'm sure it has made a difference to those that have seen it but I still don't know how to make it go viral. Especially when we can't even get all of our members to view it.

We need more financial, physical, accessible, safe environments and tools to participate fully. Oral traditions, cave paintings and dance, even in the face of oppression were all vehicles for education and better understanding self and of each other. But when we are constantly ignored or treated like an inconvenience, with survival-of-

the-fittest notions and self-centered over-privileged attitudes dominate our media and behaviors what chance does someone labeled 'other' have? What will that ignorance get privileged when they end up in a home, traffic or sport accident. Or if they have a child or other family member born with disability? Only then does difference or disability access entre their myopic view. Disability is the only minority any one can join at any time unexpectedly.

As Ursula Franklin often says "the political is personal and the personal is political." And Wendy Crewson says "To be an artist is be an activist".

I wonder whether a performer with a disability in a society that doesn't really seem to welcome the 'other' is committing a crime of civil disobedience by appearing in public let alone performing. There was an 'ugly' law in the USA not that long ago. Go ahead look it up. Now despite being overused and unrepresentative, the blue and white wheelchair is often the international symbol for disability. Playing with words and the way we use as communication tools and styles change and develop my curiosity to engage and adapt my own understanding of inclusion and exclusion. Just because something is packaged, is presented well doesn't mean it works cross platforms or personalities even when it is supposed to. Does art in its myriad of modalities have to work for everyone? No, I guess not, but it would be nice if we as commissioners of communication found ways to let more people play.

Am I the artist and the curator, the storyteller and the translator, the producer and the director, the writer, the set and costume builder and performer? How many hats do I have to wear to be included? If society wants to make me a spokesperson, can someone tell me how to make them listen and hear?

My performance was one iteration of a continuing, developing idea to increase visibility and inclusion. As well as the digital storytelling, and in respect of the above indignities and frustrations, I am going to share a collection of poems strung together that became the voiceover or sound track for a digital story telling project.

Prose, spoken word, couplets and a variety of styles, all these different voices reside inside of me and I share them, to further emphasize the variety of ways I adapt, cope and create a visual, visceral and textual portrait. This collection of feelings and words becomes a metaphor for certain experiences I have.

Attention and intention.

Invalid. In-valid

Through the threads of thought and the action of creation, I hope to unite all the elements. This shell some name as body parts, brings to the surface my form of awareness. I believe there is a somewhat universal socialistic perception that self-acceptance is unacceptable. Media perpetuates the notion of augmenting the human form to so-called "ideal standards".

I wish to use this media as a vehicle to somehow solidify the possibility of healing the fractures created by such propaganda. By exhibiting my memory of touch and

acceptance of another, I wish to share tangible evidence of another's form of love juxtaposed to your experience.
I wasn't supposed to happen. Finding strength in our own individuality requires courage. Sometimes we have to speak out for ourselves or for others. I think when we are touched, moved, inspired, when we see something, hear something that makes us feel deeply – we feel connected.
Somehow connection makes the ineffable tangible; the invisible felt; the silent heard.
When people see you, not just look at you; when they listen, not just hear you; when you are taken into consideration; when someone takes you into account. Not just a number, not just statistic, not just a symbol or a label.
Don't get me wrong – I know stats, symbols, logos, and labels are important. Have you ever thought of why they are important?
What they mean?
They are evidence that someone was paying attention; They are designed to be recognizable; they are designed to represent something - that matters – something familiar, something you can relate to.
As human, we feel compelled to share what we have learned
To teach what we know
To protect – to show we care
To connect with each other
We look for the familiar, recognizable, the same
Even though we feel different
I AM DIFFERENT
I am a visual artist, a dancer and an actor
Humans used movement, sound, which turned into storytelling years before stage, screen, or machine
I am an activist. I like to propel, provoke, promote and perpetuate change
Sometimes I do it in subtle ways and sometimes in strong
2 B
2 B in
In De PEN Dance
Writing is a pen dance
Can I describe? Can I de-Scribe?
Or record
An experience
By making marks on a surface
Is there a right way?
A wrong way
Or a better way

Is my experience that different?
that similar to yours, theirs, hers, or his
I am merely one who seeks, longs, desires,
wishes to find my way or place in the world
Does that make me unique?
Strange?
Or Special?
I'm not more or less important than you
But I feel more than less important
I don't hate you when you hurt me
But the anger you see
Or Don't see
Is.
Do I learn from you?
Do you learn from me?
I hope so
But what do you intend to teach
By your behavior
Did you know your behavior?
Teach others
You
Mirror for some
For others
I can't speak
Though I have tried before
And maybe
I will try again
For now
I am aware of my own behavior
For now
I speak for myself
For now
I intend
Not to act out my anger
But pay attention to my hurt
In hopes that I will heal
Not hurt in return

I use personal materials to communicate why I feel compelled to be an advocate. I speak out, act out, because I can. I have fashioned my own sound byte to illustrate. "I have been stared at my entire life; why not find ways to get paid for it?" (From an interview with Ted Fox on

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