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Editorial Isolation: A Diary of Subtle Discrimination

Megan A. Conway, PhD
RDS Managing Editor

I was recently asked to write a forward to a book about the portrayal of disability in literature. When I asked what the author would like me to highlight, he suggested something about progress that has been made and progress that has yet to come about attitudes towards people with disabilities. Progress. We are always striving forward towards progress, measuring our progress and the progress we have yet to achieve. Always talking about the way it used to be and always hoping for something better for the future.

In a recent class discussion for my Introduction to Disability and Diversity course, we talked about the institutionalization of people with disabilities. The students had been asked to view a video called "When the Moon Comes Up" (<http://www.youtube.com/watch?v=k2OxpzPybT4>) by Norman Kunc, who talks about how his parents made the choice to raise him at home rather than have him institutionalized as the doctors suggested. The film shows Kunc with his wife and children, on the job, sailing his sailboat, and then transitions to photos from the 1960s of inmates at a residential institution for people with developmental disabilities accompanied by a haunting lyric, "When the moon comes up, it shines on them too, cut them and they bleed..." The film ends with Kunc saying, "It is sobering to realize how much the course of a life can be altered by a single decision."

"That was a really powerful video we watched," commented one of my students, "I'm so glad we don't have institutions like that anymore. It's so good that people with disabilities can now receive services instead of being stuck in a place like that." And so I had to explain that no indeed, there were still institutions where people with disabilities were stuck. Maybe, at least in the United States, they are not quite like they used to be. You don't see images of naked starving people covered in feces wandering the halls like the images that we saw in the film, but there are still people who could easily tell you how other people's misperceptions and power has adversely affected their lives. Can we pat ourselves for making progress in this area? Not really.

But then I read the article in this issue of RDS that compares the experiences of visually impaired people in Peru and Jordan, an article that celebrates the progress that these two countries have made in access for people with disabilities, but also highlights the inequities that still exist, especially when compared to my own experiences as a visually impaired person in the United States. As I sit here typing on my new computer with the latest enlargement software, listening to the tap of the keys with my spiffy Bluetooth-enabled, state-of-the-art hearing aids, pondering life as a college faculty member, I am reminded of what progress can do. Progress is possible, and progress is something to aim for.

As we celebrate and conclude our tenth volume of RDS, we also conclude the end of our print edition. We have been proud to be one of the only disability studies journals still offering a print edition, but progress, it seems, has caught up with us. Onward into the exciting world of web-based products and multimedia possibilities. May we look back ten years from now and see where we made progress too!

Art History and Disability

Ann Millett-Gallant

University of North Carolina, USA &

Elizabeth Howie

Coastal Carolina University, USA

Forum Introduction

Art history has not been as engaged with disability studies as much as have other areas of the humanities and liberal arts. Disability studies scholars have written about artwork featuring disabled subjects and the work of disabled artists, engaging varying degrees of art historical methodology, whereas art historians have analyzed images by and about disabled people with limited awareness with disability studies. This special issue aims to encourage more interdisciplinary work between the fields and was inspired by three conference panels at the Southeast College Art Conference: *Visualizing Disability: Representations of Disability in Art and Visual Culture* (2011), *Disability and Performance: Bodies on Display* (2012), and *Photographing the Body* (2013).

For art historian W.J.T. Mitchell (2005), a work of art is an object that asks us to look at it. Not only that, we may judge or evaluate it, as well as respond to it emotionally, and it often includes representations of the human form. For these reasons it is imperative that issues central to art history and disability studies related to looking/staring/gazing, expectations and stereotypes, and conformity and difference be considered. Both disability studies and art history are inherently interdisciplinary, and the scholars' approaches in this issue reflect this, drawing on aesthetic theory, psychoanalysis, semiotics, sociology, phenomenology, and reception theory. They bring together the work of disability studies scholars like Rosemarie Garland-Thomson, Lennard J. Davis, Tobin Siebers, David Hevey, and Ann Millett-Gallant with the work of scholars more associated with art history and visual culture such as Abigail Solomon-Godeau, José

Esteban Muñoz, Linda Nochlin, John Berger, John Tagg, and Susan Sontag. The works under consideration here range from a sixteenth-century portrait to a twenty-first century graphic novel, with two essays examining photographic images relating to disability. The essays address both works representing individuals with disability and work by artists with disability. They contextualize understanding of disability historically, as well as in terms of medicine, literature, and visual culture. All of these essays demonstrate the rich rewards of the type of sustained close looking which characterizes art history at its best. And as the essays dealing with more contemporary works attest, there is a clear interest in contemporary art in the exploration of representation of disability. This interest may also reflect a growing awareness of issues related to disability in present-day scholarship, society, and visual culture.

In this issue, Sara Newman analyzes a sixteenth-century portrait of a woman with facial disfigurement by Quentin Matsys, *A Grotesque Old Woman*, in a variety of historical and art historical frameworks. Newman contrasts contemporary definitions of disability according to the social model, with sixteenth- and seventeenth-century European medical, religious, and municipal models. Using an art historical methodology of comparing this portrait with other conventional forms of portraiture from similar social and cultural contexts, Newman discusses how the status of citizens whose bodies deviate from the "norm" varies according to time and place.

Nina Heindl examines *Acme Novelty Library*, a graphic novel by comic artist Chris

Ware, discussing how the novel represents a disabled female character through the relationship between image and text. She compares the novel to sculptural and performative representations of female amputees, specifically in the work of Marc Quinn and the performance of Aimee Mullins in Matthew Barney's film *Cremaster 3* (2002). Heindl also engages aesthetics of perception to argue that the viewer/reader constructs the meanings of the representations, how one perceives disability in representations depends on context and formal qualities, as well as the subjective experiences the viewer/reader brings to the exchange. Heindl's argument demonstrates that how disability is constructed socially and politically relates to how it is perceived visually and textually.

Timothy Hiles analyzes photographs of disabled people by Gary Winogrand, Elliot Erwitt, Robert Frank, and Diane Arbus against a historical background of the American Civil Rights Movement and an increasing awareness of cultural diversity. He asserts that these images stereotyped disabled individuals as outside their communities and articulated their exclusion from the "norm," while, in some cases, claiming to show empathy for these "others." Hiles's argument demonstrates how visual and artistic representation both reflects and contributes to the social construction of disability.

Amanda Cachia focuses on the work of two dwarf photographers, Ricardo Gil and Laura Swanson, and how they frame the dwarf subject. She contextualizes their portraits and self-portraits in a history of photographic representations of individuals of short stature, specifically by Diane Arbus, Arthur Fellig (or "Weegee"), Mary Ellen Mark, Bruce Davidson, Garry Winogrand, and Joel Peter-Witkin. Discussing strategies of revealing and concealing the body and analyzing dynamics of the gaze/stare, Cachia argues that Gil's and Swanson's photographs showcase more dimensional aspects of dwarf subjectivity and an embodied perspective of a dwarf.

It has been such a pleasure to work with these innovative and insightful scholars, and we are grateful to the editors of the *Review of Disability Studies* for giving us this opportunity to expand the dialogue between art history and disability studies.

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Composing Dwarfism: Reframing Short Stature in Contemporary Photography

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Forum Articles

Abstract: This paper will explore the work of two contemporary dwarf photographers, Ricardo Gil and Laura Swanson, who use different conceptual and technical methods to re-frame the figure of the dwarf subject. The dwarf has often been a marginalized subject in the history of photography, so I am interested in exploring how the strategies that Gil and Swanson employ might resist reductive meanings, and offer alternative readings to the dwarf beyond the oppositional gaze. The articulation of these methods will be prefaced by a focused discussion of dwarf depictions in the history of photography based on the intentions of the photographer, so that the work of several photographers might be powerfully juxtaposed with the radical counter-strategies that Gil and Swanson utilize.

Key Words: art history, Ricardo Gil, Laura Swanson

This paper will explore the work of two contemporary dwarf photographers, Ricardo Gil and Laura Swanson, who use different conceptual and technical methods to re-frame the composition of the dwarf subject. The dwarf has often been a marginalized subject in the history of photography, labeled as deviant, pathological, freak and “other,” so I am interested in exploring how the strategies that Gil and Swanson employ might resist reductive meanings and offer alternative readings to the dwarf beyond the oppositional gaze. The concept of the oppositional gaze, first put forward by critical race theorist and activist bell hooks, is where the traditionally passive marginalized subject, who is objectified under a white, male gaze will instead return that gaze to claim agency (1992). The articulation of these methods will be prefaced by a focused discussion of dwarf depictions in the history of photography based on the intentions

of the photographer, so that the work of several photographers might be powerfully juxtaposed with the radical counter-strategies that Gil and Swanson utilize.

In their strategies of re-directing the gaze of the viewer, privileging the dwarf subject and more generally re-framing depictions of the short-statured embodiment, I suggest that these artists significantly depart from the stigmatized status surrounding the dwarf’s representations in the work of non-dwarf photographers, such as Diane Arbus, Arthur Fellig (Weegee), Mary Ellen Mark and Bruce Davidson. This is because the viewer is made more aware of the psychology of the dwarf, as a means to encourage the viewer’s compassionate involvement, as opposed to attracting a historically prevalent, morbid and reductive curiosity. Art historian Abigail Solomon-Godeau says that this is an important duality in the ethics and politics of photographic criticism, in which an insider position might convey a more personal involvement in the “truth” of the subject matter, as opposed to an outsider perspective that might convey a detached observation of a mere object and spectacle (Solomon-Godeau, 2004). Troublesome photographer/subject relationships have often left behind traces of controversy around power, control, and moral and ethical responsibility, leading to stigmatization of the subject at hand.

This paper will therefore use Solomon-Godeau’s duality theory as a jumping-off point, to consider the following critical questions: Can we trace a distinctive, more complex disability politics in photographs at the hands of disabled, or in this case, dwarf photographers, where a new discourse around intersectional identity and complex embodiment can be found? How do these photographs move beyond one-

dimensional readings of portrayals of disability, to add more representational layers to disabled corporeality? What are the implications of photographers who do not identify as disabled, but claim to offer more sensitive readings of disabled groups as an alternative to the freak or outsider constructs, and those photographers who do identify and are empowered by the technology that is firmly in their grasp?

The power and agency held by Gil and Swanson may foster different perceptions of dwarfism that have received scant attention in art history and criticism. These readings may shed light on, in Solomon-Godeau's words, the "inside" of the dwarf (Solomon-Godeau, 2004). The viewer may come to know the dwarfs differently through their revealing acts, which cannot otherwise be understood from a non-dwarf photographer's perspective. Most importantly, we learn to see the dwarfs from both behind and in front of the camera, with full knowledge that they are the ones in control of both sides of its lens. However, determining what is reductive or non-reductive in relation to the representation of the dwarf in contemporary photography has many more shades of grey than meets the eye.



Figure 1

The Ambiguities of Dwarfism in Historical Photography

In this section, I will focus on two strategies that reveal how the dwarf has been depicted in the history of photography. I argue that these strategies exploit the mainstream desire to look at the dwarf's unusual anatomy, despite any well-meaning intentions of the photographer. These reductive and oft-implemented strategies offer the dwarf as either featured in the nude, or as a circus performer.

First, I will examine the work of non-dwarf photographer George Dureau. In an interview, dwarf photographer Ricardo Gil said that he believed Dureau wanted to take photographs of dwarfs because he admired their unusual proportions (Gil, 2013). Psychologist Betty Adelson supports Gil's position, because she says that Dureau was interested in demonstrating his appreciation of the male body and made a conscious effort to "dislodge stereotypical, negative assumptions about the bodies of individuals with physical deformities" (Adelson, 2005, 177). Dureau took many photos of dwarfs in the nude, or some posed with minor embellishments or props like a hat. For example, in *Short Sonny* (ca. 1970, fig. 1), a black man with the most common type of dwarfism, achondroplasia, poses in this black and white photograph, wearing a decorative turban that is suggestive of Oriental tropes. The African- or Middle-Eastern-inspired head-dress was meant to evoke romantic imagery, which recalls a genre of Orientalist photography which allowed, as art historian Linda Nochlin says in the context of Orientalist painting, "the (male) viewer...[to] sexually to identify with, yet morally distance himself from, his Oriental counterparts depicted within the objectively inviting yet racially distancing space of the painting." (Nochlin, 1989, 45). I argue that Dureau is calling on these tropes to reactivate strategies to similar those of such Orientalist photographers, where the burden of both Oriental and dwarf representation is combined

to retain the captivation of the mainstream gaze to its most extreme point.¹

The man in Dureau's photo stands off to the side, his back and buttocks facing towards the viewer, his hands placed on his hips. He is by a window with light pouring in, and he looks out of the corner of his eye back at us, almost as if he is trying to catch the viewer in the act of gazing upon his nude form. It is hard to determine if his gestures are meant to demonstrate pride in his nude body's appearance, or indignant protest. Is he questioning why he must be looked at in this way? Doesn't the nudity amplify our interest in the dwarf's unusual form even more? Again, it is as if Dureau's admiration and curiosity were moved to the point of shedding layers of clothing in order to take full advantage of the delight a viewer would have in gazing upon the dwarf's atypical corporeality. Further, despite the fact that this dwarf looks back at us looking at him, how much empowerment is Dureau giving his subject here?

Dureau's imagery is complicated by the fact that Dureau had a so-called insider status, according to Gil, who posed for Dureau many times, both in the nude and with various articles of clothing, and claims that Dureau is a friend to this day (fig. 2, fig. 3). The earnestness



Figure 2

expressed by Gil regarding Dureau's authentic intentions cannot necessarily be transferred to the surface of Dureau's portraits of dwarfs. How is it possible to determine Dureau's insider status from simply looking at an image? Rather, I would argue that it is all too easy to categorize and label such work as part of a historical trajectory of images of dwarfs who are partially or fully stripped of their clothing in order to titillate the voyeuristic gaze.



Figure 3

For example, the infamous *Mexican Dwarf (a.k.a Cha Cha) in His Hotel Room*, (1970) by Diane Arbus, and *Drinking In Style*, (1943, fig. 4) by Arthur Fellig (Weegee), amongst others, posit the dwarf in various forms of undress.² Several scholars, such as David Hevey, suggest there may have been an erotic or sexual relationship between the dwarf and Arbus that can be construed from looking at *Mexican Dwarf (a.k.a Cha Cha) in His Hotel Room*; however, I argue that this doesn't necessarily nullify the sensationalistic and voyeuristic opportunity the image now provides for an audience that continues to associate the dwarf within very particular, narrow stereotypes (Hevey, 2010). While on the one hand Ann Millett-Gallant says that the dwarf is an empowered sexual being in the Arbus photo, given the way he also meets the viewer's gaze flirtatiously, accompanied by a somewhat smarmy smile, his overt sexuality might also be interpreted as indigestible, dirty and even sleazy (Millett-Gallant, 2010). In Fellig's image, the dwarf stands at a bar dressed in a diaper, while

holding a beer and donning a 1943 party hat. Betty Adelson says that he is “clearly intended to be an amusing emblem of ushering in the New Year,” much like the still commonly-practiced ritual of inviting dwarfs to events and/or parties



Figure 4

in Hollywood in order to amuse guests (Adelson, 2005, 167).

It is also hard to imagine that an elevated status of the nude dwarf might be on par with the revered status of a classical Greek nude statue, whose corpus was meant to espouse the utmost qualities of perfection, proportion and beauty, given what we know about the history of the dwarf consigned to the status of a freak. In other words, while the nude figure of so-called perfection was to be admired, the nude figure of imperfection was historically meant to be gawked at. So while the intentions of Dureau and Arbus may have been earnest, do these images of the nude dwarf evoke such intentions, or do they continue to problematize dwarf as “other”?

To further drive home these points, I would now like to consider photographs that depict the dwarf as a circus performer. Adelson says that a “remarkable number of photographs have been of clowns, reinforcing the image of dwarfs as clowns in the minds of the public” (Adelson, 2005, 167). The two images that Adelson examines include Mary Ellen Mark’s photograph, *Twin Brothers Tulsi and Basant (Great Famous Circus, Calcutta, India)*, (1989, fig. 5) and Bruce Davidson’s *The Dwarf* (1958, fig. 6) that depicts the Jimmy the Clown. In both of these photographs, the dwarf appears on the circus grounds, in what look like grim conditions. Both photos are taken from the perspective of average-height photographers, as we are looking down on these forlorn creatures. Mark’s photo shows twin dwarfs dressed in gorilla costumes, a device used by the circus to emphasize the dwarfs’ animal-like status in the community, to accentuate their historically-subservient role as entertainers and laughing stock. One twin has taken the head-piece off, and stares back at the viewer with a dejected expression, while his brother stands off to his side in full garb. This photo looks as if it is taken from an angle, as if to emphasize the quirkiness of Mark’s subject matter. Adelson goes on to describe Mark’s experiences capturing images of the twin brothers and their circus colleagues. Mark also talks of the beauty and ugliness to be found in the circus, and that she wanted to demonstrate to viewers that these circus characters are victims by portraying them in a sympathetic, caring light (Adelson, 2005, 168-169). While the effect of the oppositional gaze that one of the brothers brandishes is important to Mark’s strategy, (we detect the oppositional gaze by the way he confronts the viewer directly and by his assertive body language and facial expression), does this offset the context in which the image is shown, i.e. that of the circus? While the viewer may sympathize with the angry dwarf in the circus, the viewer may also understand that the dwarf is perpetually confined to the circus, distinguishing pathology from normalcy, and

keeping the freak at a distinct distance from the so-called average subject.

A remarkable similarity in composition may be detected in Bruce Davidson's image of Jimmy the Clown, who inhales from a cigarette with one hand, while gripping a bunch of wilting roses in the other. Jimmy does not look back at the viewer in protest regarding his glum circumstances, as demonstrated in Mark's photo, yet he does gaze off into the distance, his facial expression bearing antithetical traces of any stereotypical qualities attributed to the merry comportment of a clown. Whilst the sad clown is also a prevalent trope, Jimmy's penetrating gaze thwarts the made-up expression of the falsely-sad clown stereotype. Jimmy is alone, and his exaggerated clown make-up only serves to accentuate his true sadness, marking a too-easy transition of his character portrayal into his real-life role as a servant to mockery and jest.



Figure 5

Again, Adelson comments on the fact that Davidson had personal relationships with his dwarf subjects, particularly with Jimmy, who became his friend, therefore also confirming Davidson's role as privileged insider, alongside Goldin, Dureau and Mark (2005, 168-169).

As a counter-strategy to the problematic frameworks of dwarf as nude or dwarf as circus performer, I turn to Gil and Swanson who are dwarf photographers concerned with rupturing the mainstream voyeuristic gaze that wants to reduce their dwarf bodies to the level of "other"

or freak. By engaging in radical performative acts before the camera, the dwarf photographers "perform disidentifications," a term coined by the late José Esteban Muñoz, as a means to provide a strategy of resistance or survival for minority subjects, while also acknowledging its limitations (Esteban Muñoz, 1999, 5). I argue that in performing disidentifications, the photographer with agency must now do something more than simply have his or her subjects stare back at the viewer, so that the photographers activate their work differently from that of so-called "insider" photographers like Dureau, Mark, Davidson and even Arbus. In this way, their photographs

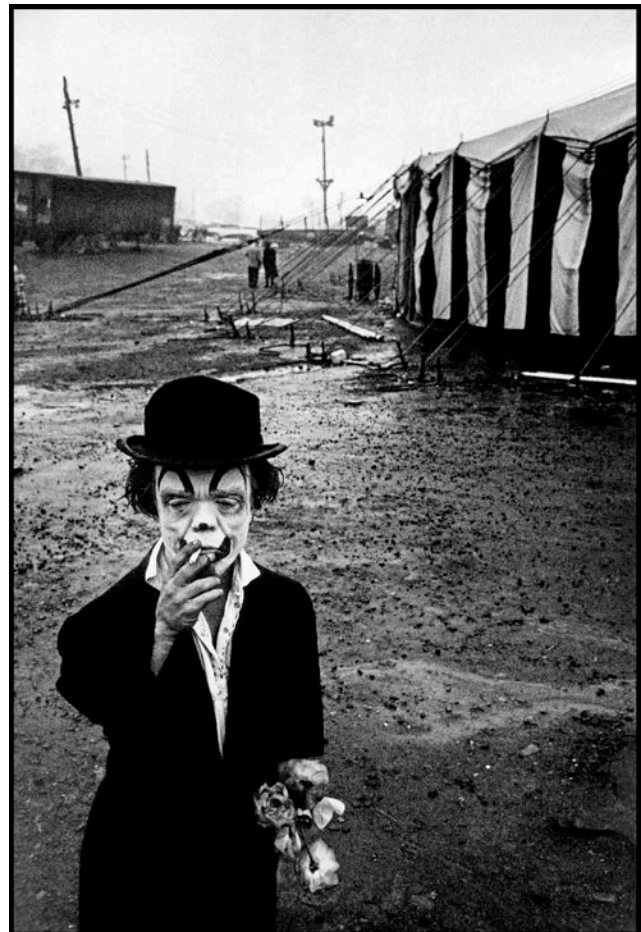


Figure 6

will register as transformational in how people might perceive the dwarf. Further, Dureau, Mark and Arbus place the dwarf in contexts that the mainstream public is all too familiar with; they are comfortable with the trope of dwarf as

nude or dwarf as clown, and so the insider-positions of Dureau, Mark and Davidson become meaningless given that we can only judge an image by its cover.

If Solomon-Godeau says that this is the quandary of photography, where its ontological status is one limited to exteriority, how can the dwarf photographer ever hope to get beyond appearance and make viewers aware of the dwarf as person, as more than object, if they only have a glossy surface to rely on? Will the burden of their own appearances get in the way of more desirable depictions that are deeper and more complex to shed light on the rich lived realities of the dwarf? Can dwarf photographers eschew deeply-embedded assumptions through the surface of the image? It is at this crucial point that I would like to suggest that the work of Gil and Swanson does much to enact lines of counter or subversive photographic strategies. In their work, it is possible that through the dwarf's very exteriority, we come to understand the subject's interiority beyond simply an oppositional gaze. In fact, the oppositional gaze is no longer a cutting-edge methodology to use in thinking about the dwarf's interiority or exteriority. I will now move into a detailed discussion of their work.

The World Looking Up: The Photographs of Ricardo Gil

In the 1990s, Gil took photographs of his then wife, Meg, and child, Lily, from his perspective, which is a height of 3'9". He set out to present a portrait of two people that were intimate in his life, in, he says, the most powerful and beautiful way. During an interview with Gil, I asked him about the unique nature of his compositions, where average height people are more or less

cut out of the frames, and usually only their legs can be seen, given the remainder of their bodies are not within Gil's focal radius. He said that average-height people were simply out of the frame - sometimes they were included, and sometimes they weren't: "I'm sorry, there's a lot of stuff going on down here, and sometimes average-height people are not privy to it" (Gil, 2013). Gil went on say that some photos are tongue-in-cheek, while others are not. The artist was especially interested in using average-sized people as props, like a column or a prop on a stage. While on the one hand, Gil will say that his viewpoint is not especially unique, given it is just his viewpoint, (and after all, what other viewpoint would he use?), on the other hand, his viewpoint is a big deal because rarely do we come upon his perspective in the annals of art history or even contemporary photographic art practices. The visual stance of the dwarf means that average-height people are reduced to just their legs, given that is what fills most of the dwarf's sight-line.

In *Walking Man and Mannequins*, by Gil (c. 1996, Fig. 7), a row of average-height mannequin legs wearing various pants and jeans with white socks on their feet are lined along a street pavement in front of a store. Gil snapped the



Figure 7

photograph just as a man (also wearing jeans) was quickly walking past. Only the man's walking legs and feet, with black shoes, in motion, and a swinging blurry arm at the side of a torso are visible. The image is a powerful constellation of pairs of legs in Gil's sightline, where both the still and moving forest of body parts work together to exemplify Gil's focal point. Further, the "half" bodies of the mannequins contrast with the walking man's figure, which the viewer might understand as "whole," even if his upper body is cut from the frame. This jumbles up ideas of body sizes and shapes in general, and



Figure 8

serves to prompt questions about what is normative or atypical, in parallel with Gil's unusual frame of view as photographer.

In the next two photographs (fig. 8 and fig. 9), Gil's ex-wife, Meg, appears engaged in various activities. In the first, *David's Kitchen* (1997), she washes dishes in a kitchen wearing formal clothing and talks to an average-height man. An average-height woman who appears to her right is engaged in putting away the dishes. In the second photo, *Gil, Charles, Eric and Meg* (1999), Meg is laughing and waving as she talks to two average-height men in suits with ties. This looks like a formal event again, as Meg wears another nice dress. Of course, what is distinct about these images is how the focus is on Meg and her perspective. Meg looks up at the men as she talks to them. We see her eyes and/or her head titling up, while the men look down, or we

can only imagine them looking down at her. But it is clear that Meg is the main character, and it is her body that we see in full perspective, rather than looking down upon her as other photographers in the past have done. Meg is centralized while the average-height people are, as Gil says, Meg's props to frame her corpus, like Greek or Roman columns.

Gil's photos are in stark contrast to several street photos by Garry Winogrand (fig. 10 and fig. 11), where either the dwarf or the amputee homeless man is captured from Winogrand's perspective, which can be estimated between five and a half to six feet tall. In David Hevey's key essay, "The Enfreakment of Photography," the author says that "Winogrand consciously or otherwise included disabled people with the specific intention of enfreaking disability in order to make available to his visual repertoire a key 'destabilizing' factor" (Hevey, 2010, 515). We look down on these unmentionables just as Winogrand did, both literally and metaphorically in a classist, ableist way. Looking down implies distaste, snobbery and judgment, and such



Figure 9

a physical gesture places Winogrand's image in the realm of the voyeuristic, regardless of Winogrand's actual intent, or inside/outside relationship with his subjects.

Gil said that initially, when he started playing with his field of view, he did not realize he had something unique to offer in this way. He didn't really know of any other dwarf photog-

raphers using this strategy, but he did know of a number of other artists and photographers with disabilities, like Kevin Connolly, who was



Figure 10

born without legs and uses a skateboard to move around. Connolly has taken hundreds of documentary photographs of people staring at him in his journeys throughout the world. Connolly's photos (fig. 12 and fig. 13) show the shocked looks of people across the spectrum in age, race and gender, gazing down at Connolly's unusual embodiment, as he/we look up at them. Both Ann Millett-Gallant and Rosemarie Garland-



Figure 11

Thomson focus on the power of the stare or the gaze that Connolly has most effectively captured and inverted through his photographs, while Millett-Gallant also mentions that the "camera's lowered perspective and viewing angle upward reveals Connolly's perspective..." (Garland-Thomson, 2002 and Millett-Gallant, 2008). Like Millett-Gallant, I argue that Gil and Con-



Figure 12



Figure 13

nolly's photographs "exhibit disability as a way of seeing from an embodied, indeed empowered, perspective" given not only the uniqueness of their perspectives, but the fact that we rarely get to see photographs from this perspective (Millett-Gallant, 2008).

Ultimately, like Connolly, Gil knew that the power behind his own self-portrait was because it was the man himself composing the images, making a statement about his own community, saying, "this is me, this is us." (Gil, 2013). Gil wants people to metaphorically and even physically "get down on their damn knees to look at the work" (Gil, 2013). And it is down on their knees that an average-height visitor will gain a new perspective on the dwarfed viewpoint, according to Gil.

To Conceal Is to Reveal: The Anti-Self Portraits of Laura Swanson

Laura Swanson is a Korean-American artist whose practice has been influenced heavily by her everyday experiences as a short-statured person. Swanson's photographs question the conventions of looking at bodies that are different in height and size. In *Anti-Self Portraits* (2005-2008), Swanson's attempt to hide her body within different domestic scenes is paradoxically humorous and poignant. By conspicuously denying her identity to the viewer, Swanson's photographs go beyond an examination of representation in portraiture by questioning the desires behind wanting to look at difference. In each image, the artist has obscured or covered her face, drawing attention to the fact that she is withholding something from her viewers. In the four images here, we see a) Swanson standing in a hallway, almost completely covered from head to thigh by a large brown coat attached to a coat hook on a wall (fig. 14), b) a large, red and white checkered bedroom pillow covering Swanson's body as she sits on a bed (fig. 15), c) Swanson's face and upper torso covered by shaving cream as she rests in a bathtub (fig. 16), and d) Swanson's face hidden by an album cover of a 1960s



Figure 14



Figure 15

female singer, as she stands in a living room (fig. 17). The difference in this final image is that Swanson doesn't cover her entire body, but just her face – her dwarf body is revealed underneath the album cover. Swanson calls these her "faceless portraits" or "anti-self portraits" where she hides in plain sight.

Through these acts of concealing, Swanson is actually revealing her vulnerabilities, fears and frustrations over being judged and stared at, simply because of her atypical embodiment. The viewer is thus invited to connect with her in an intimate way, without necessarily having to see her face. Swanson acknowledges that the history of photography is riddled with images of the "other," and thus her *Anti-Self Portraits* are "a response to the problematic images that [invite the public] to gawk at otherness – images that continue to stigmatize many groups of people"



Figure 16



Figure 17

(Bonner, 2013). According to journalist Kelly Inouye, Swanson is in fact managing to reveal an "inside" unlike most of the photographers that Solomon-Godeau mentions, because Swanson is performatively showing us her innermost feelings and insecurities by hiding and in turn, protesting. Thus, Swanson may desire to hide, shield or protect herself from prying, gazing eyes, yet she actually reveals more about

how she feels through her act of concealing, than if she had employed the common trope of the oppositional gaze.

I am particularly interested in Swanson's equally empowering strategy in using makeshift masks to hide her identity and her facial expression from the viewer. Countless images in photography depict the "other" wearing masks, ranging from the work of Diane Arbus to the contemporary artist Joel-Peter Witkin. Millett-Gallant makes reference to Judith Butler's theorizing on the use of masks, arguing that "masked subjects invite, block, and mock the viewer's gaze" (Millett-Gallant, 2010, 37). To put this in context, she discusses Arbus' photograph entitled *Masked Woman in a Wheelchair* (1970). The mask becomes more than just a costume piece, for it acts as a device for shielding the physiognomic information attached to viewing her face, therefore also deflecting reductive readings of or associations with her countenance as a wheelchair-user. As Millett-Gallant says, "The face is considered the visual marker of who one is, and facial features are common targets of exaggeration and manipulation..." (Millett-Gallant, 2010, 137-138). The mask that this woman wears, in addition to the creative masks wielded by Swanson in her anti-self portraits, symbolize agency for the subject at hand, given they do much to prove that identity is fluid, dynamic and unpredictable, and that we cannot rely on the simple judgment of a facial expression, or even an empowering oppositional gaze. Just as Arbus' *Masked Woman in a Wheelchair* takes the oppositional gaze one step further by gazing back at the viewer, so too does Swanson's performative and bodily acts reverse the normal tropes of portraiture.

But the mask can also be wielded by a photographer in yet even more complicated ways. For instance, in *Dwarf from Naples* (2006, fig. 18) by Joel-Peter Witkin, the artist has presented the viewer with a nude portrait of a female dwarf with achondroplasia who wears a white-cloth, cartoon-like elephant mask.



Figure 18

She wears long black gloves, holds up a short wand or conductor-style baton, and stands in a studio supported by other props, such as a skull lying on its side and groupings of vegetables suspended from the ceiling. All of these elements, in addition to her posture and her body language, speak to the dwarf's erotic mastery over her environment and her own atypical corpus, which could be construed as empowering. However, by masking her face with a cartoon-like elephant veil, Witkin is providing the viewer with uncensored viewing pleasure of the dwarf's nude form, while also mocking her through the derogatory mask. Further, Witkin places the dwarf squarely within the context of historical venues that showcased striptease and burlesque dancers, which is indicated by the style of her clothing, the set and props, and her posture and body language. Showcases like this may not have ordinarily included imperfect dwarf bodies. On the other hand, given the history of the dwarf body on display within the trajectory of freak shows and similar spectacles in the same time period, this image serves to reinforce

and continue this perverse tradition. Thus, the photographer precariously straddles bestowing agency on his subject, and yet consigning her to the same voyeuristic, normative gaze, as many others have done before him.

The examples presented here demonstrate the core issues being grappled with in this essay – what constitutes inside/out, and if the photographer's intent as "truth" can ultimately be determined by examining the ontological surface of a photograph. In my analyses here, I have aimed to capture the paradox and ambiguities of the inside/outside paradigm, whilst simultaneously avoiding any simplistic positive/negative reading; rather I point to complexities. Given, as art historian John Tagg says, that strategies of representation (and its burdens) have gone largely unchallenged by both mainstream photographers and critics, I hope the work by these dwarf photographers begins to address some of these issues (Tagg, 1993).

Conclusion

Despite the complexities of the positive or negative readings that might be construed in examining the representation of the dwarf in both historical and contemporary forms of photography, or in thinking about the ambiguities in relation to Solomon-Godeau's inside/outside binary, the fact remains that within this history, rarely do we come upon depictions of dwarfs as interpreted through a dwarf lens. Even less do we come upon focused scholarly attention on work that has been or is being executed by dwarf photographers, so through my study here, I hope to fill in some of these spaces in art history, addressing the unique mode of perceiving dwarfism through the dwarf photographer perspective. Tagg speaks of how critical this determinate space becomes, given it opens up conversations around the nature of power "which [is] brought to bear on practices of representation" (Tagg, 1993, 21). Given that recent photography theory has begun to prize open the legitimacy of the dominant/insubordinate power

relations in photographic representations, it is at this juncture that Tagg argues we create this very space for acknowledging that power is no longer uniform, unified, general and only “emanating from one privileged site” (Tagg, 1993, 21). The criticality of this space therefore “exposes a rift...in the general conceptions of representation on which they rest” (Tagg, 1993, 21). It is through the work of the two dwarf photographers here that an awareness of this rift becomes more pronounced than ever before.

Further, we must continue to understand that while the photograph is a mere material item, it exists and is consumed within a wider complex of social relations and ideological constructions which feed into its meaning. By noting the counter strategies that Gil and Swanson propose in their photographic representations of dwarfs, we may also witness their effective “unmasking” of any prescribed “truth” to any ideology that is meant to convey reality. In essence, these photographers confront ostensible “truth” with their own ideologies, which effectively reflect their opposed outlook. Finally, as Solomon-Godeau summarizes, “It may well be that the nature that speaks to our eyes can be plotted neither on the side of inside nor outside, but in some liminal as yet unplotted space between perception and cognition, project and identification” (Solomon-Godeau, 1994, 61). I suggest that beyond the oppositional gaze, the radical counter-strategies and intersectional, compositional devices that Gil and Swanson offer for reframing the dwarf subject might begin to chart some of this liminal, unplotted space that Solomon-Godeau outlines, thereby finally opening up the possibility for the dwarf to find a new stature in art history and photography.

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Image Credits

Figure 1: George Dureau, *Short Sonny*, ca. 1970, photograph courtesy of Arthur Roger Gallery

Figure 2: George Dureau, *Ricardo Gil*, ca. 1970, photograph courtesy of Arthur Roger Gallery

Figure 3: *Ricardo Gil and George Dureau*, 2012, photograph courtesy of Jason Kruppa

Figure 4: Arthur Fellig (Weegee), *Drinking In Style*, 1943: Shorty, the "Bowery Cherub" celebrates New Year's Eve at Sammy's Bar, in the Bowery district of New York. © Weegee (Arthur Fellig)/International Center of Photography /Getty Images

Figure 5: Mary Ellen Mark, *Twin Brothers Tulsi and Basant (Great Famous Circus, Calcutta, India)*, 1989, photograph courtesy of the artist

Figure 6: Bruce Davidson, *The Dwarf*, 1958, photograph courtesy of Magnum Photos, New York

Figure 7: Ricardo Gil, *Walking Man and Mannequins*, c. 1996, photograph courtesy the artist

Figures 8 & 9: *David's Kitchen*, 1997, and *Ricardo Gil, Charles, Eric and Meg*, 1999, photographs courtesy of the artist

Figures 10 & 11: Garry Winogrand, *New York*, ca. 1968 and *American Legion Convention*, Dallas, Texas, 1964 © The Estate of Garry Winogrand, photographs courtesy Fraenkel Gallery, San Francisco

Figures 12 & 13: Kevin Michael Connolly, *Girl; London, England*, 2007, and *Man; Reykjavik, Iceland*, 2007, photographs courtesy of the artist

Figures 14 – 17: Laura Swanson, *Anti-Self Portraits*, 2005-2008, photographs courtesy the artist

Figure 18: Joel-Peter Witkin, *Dwarf From Naples, Rome*, 2006 © Joel-Peter Witkin / photograph courtesy Catherine Edelman Gallery, Chicago

Endnotes

¹ For more information on Oriental photography, please refer to Mary Warner Marien's *Photography: A Cultural History*, Second Edition, (London: Lawrence King Publishing, 2006).

² Other photographers who depict nude dwarfs include Joel-Peter Witkin and Vivienne Maricevic.

Portrait of Sixteenth-Century Disability? Quentin Matsys's *A Grotesque Old Woman*

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Forum Articles

Abstract: Scholars rarely examine art works from a disability studies perspective; their analyses often misinterpret those works, reinforcing contemporary assumptions about disability and its past representations. Accordingly, this paper examines a portrait by sixteenth-century Antwerp artist Quentin Matsys (1466-1529) from a historically situated disability studies perspective. *A Grotesque Old Woman* (c.1513) has been understood in terms of abnormality. Existing scholarship has suggested that she represents physical, gender, and sexual deviance in the spirit of Erasmian allegories, or an individual with Paget's disease. Although these interpretations may inform contemporary scholarship, they shed little light on sixteenth-century disability and its artistic representations. This paper demonstrates how the portrait reflects a cultural transition from an earlier collective, religious model of disability to a more "municipal" one which considers disability vis-à-vis individuals engaged in daily commercial or personal activities. This analysis provides insight into how disability was understood in Matsys's time, contributes to our understanding of the Dutch allegorical and portraiture traditions, and demonstrates what a historically situated disability model offers future research on artistic representations of disability.

Key Words: art history, Netherlandish portraiture; the grotesque

"I've always been intrigued by this painting. It's fascinating because it is so meticulously and lovingly painted. You think, why would someone go to so much trouble in order to paint such a grotesque image? I always suspected there was something more to it than just a study in grotesquerie" (Brown, 2008).

Although scholars of disability studies and art history often examine art works and artists, they do so primarily from their separate disciplinary vantage points. Some disability scholars have developed theories about aesthetics or considered the works of artists with disabilities, or works that take disability themes (Garland-Thomson 1996; Siebers 2010); some art historians have applied visual or medical theories of the body to disability-themed art or to the work of disabled artists (see opening quotation).¹ This scholarship addresses calls to extend the influence of disability perspectives into other disciplinary realms (Garland-Thomson, 2013; Linker, 2013, pp. 503, 524). Yet, these efforts share no inclusive perspective and, as such, often misinterpret art works within their historical contexts and/or reinforce contemporary assumptions about disability and its past representations.

At present, the term "disability" is a contested but useful placeholder with which to characterize how groups and individuals have perceived and valued human physical attributes throughout recorded history (Garland-Thomson, 2013; Linker, 2013). As this history reveals, most Western societies have marginalized people with physical attributes which differ significantly from prevalent cultural standards. By revealing these values, disability scholars have opened the door to alternatives and exposed the predominant twentieth-century Western medical model of disability.² Because this model considers the body in terms which strictly oppose normality and abnormality, it calls on doctors to treat or cure abnormalities (Linker, 2013, pp. 518-519).

To counter this stilted perspective, scholars have offered the social model of disability; its versions acknowledge the limitless variations the

human body manifests and recognize them as differences to accommodate rather than deficits to cure (Garland-Thomson, 2013, p. 916; Shakespeare, 2006, p. 197). From this perspective, a physical impairment becomes a disability only when it limits individuals within the built social environment; a mobility issue is only a disability in places without ramps (Siebers, 2008, p. 27). Although these new perspectives help to bridge the gap between disability studies and other fields, art history, as indicated, has not yet benefited systematically from this interdisciplinary work, and thus its scholarship typically does not historicize its interpretations.

For example, medieval artist Opinicus de Canistri's illuminated manuscripts have been characterized as the work of a disabled, crazy mind, specifically in Freudian terms (Salomon 1953). Because this perspective names the artist as abnormal,



Figure 1

it follows the medical model. Yet, a twelfth-century artist could hardly have manifested twentieth-century concepts such as neurosis and the Oedipus complex. In addition to offering anachronisms, the argument neglects information about how the body and mind were understood and represented at the time, along with evidence which compares Opinicus's work with contemporaneous, presumably normal artists. Lacking that material, the analysis suggests that disability is a unified concept and one which has always been based on twentieth-century norms.

Such efforts do not locate the content or form of the works in their appropriate context within the history of disability.

Accordingly, this paper offers a situated art historical and disability studies approach, and tests it through its application to a portrait by sixteenth-century Netherlandish artist Quentin Matsys (1466-1529). As its current name and the opening quotation indicate, *A Grotesque Old*

Woman (c.1513; National Gallery, London, oil on wood, 64 x 45.5 cm) is now understood in terms of abnormality, an understanding based on and reifying the twentieth-century medical model of disability. In addition to uncovering this assumption, my alternative analysis responds to the opening question by attempting to capture why the portrait was painted and how it was perceived in its own day. I suggest that the painting was not understood as a portrait of disability, that is, of physical limitation. Instead, and in the spirit of then popular Erasmian satires, the portrait focuses on the sitter's human nature. She is no more or less a fool than

any other individual and thus symbolizes all humanity rather than one deviant person. In this, the portrait reveals shifting cultural values about the human body in a setting transitioning from an earlier religious model of disability to a more municipal one; this model frames the concept of disability within the context of cities and towns, socio-economic units with centralized governments rather than the feudal, Church-centered world of the religious model it was replacing. By combining art history and disability stud-

ies, this paper offers a more inclusive, historically based discussion of the painting, addresses broader questions about analyzing past representations of physical difference in context, and sheds some light on how disability was (or was not) represented in the early sixteenth century.

Current Perspectives on Quentin Matsys's Portrait

A Grotesque Old Woman is perhaps Matsys's best-known work. The sitter is an aging woman, who appears from the waist up in an undefined space. No ornaments, furniture or architectural features are present, only the woman against a green background. Given this simplicity, the woman's costume, including the rosebud she holds, draws the viewer's attention. She wears a low-cut black dress, gathered across the torso. The neckline reveals her aging facial and neck skin, as well as her large breasts. The crowning piece, her hat, combines a horn-shaped headpiece with shoulder-length lace. Thus far, contemporary descriptions and analyses assume that it is a painting about disability—a painting about a woman who is physically abnormal. Specifically, they interpret the image from the perspective of the contemporary medical model without considering the historical circumstances surrounding its creation. As one art historical description puts it, the canvas:

“Shows a grotesque old woman with wrinkled skin and withered breasts (partially revealed by her low-cut dress). She wears the aristocratic horned headdress of her youth, out of fashion by the time of the painting, and holds in her right hand a red flower, then a symbol of engagement, indicating that she is trying to attract a suitor. However, it has been described as a bud that will ‘likely never blossom’” (Cumming, 2008).

Although stated as if objective, the description portrays her looks and character subjectively based on contemporary stereotypes about the

body and gender. The description assumes that the audience perceived the sitter as a grotesque, embarrassing woman who could not accept the aging process, a circumstance symbolized by her abnormal, disabled body.

Others scholars apply the medical model to different, more specific purposes. Some connect the sitter with Countess Margaret of Tyrol. Her deformed maultasch, or literally “satchel mouth” symbolically called attention to her reputedly loose behaviors, they note, rendered her foolish in the spirit of Erasmus's satiric allegories and, thereby, deviant (Silver, 1984, p. 100). True, she is likely an Erasmian fool, as I discuss below, but the argument lacks any evidence demonstrating that the sitter was considered deviant. In drawing this link, moreover, the analysis follows from a reference, somewhat suspect, by Margaret's enemies to her ugliness (Silver, 1984, p. 101). No extant evidence confirms this characterization of Margaret or her connection with this painting. Because Margaret died some 150 years before this painting was made, because of the costume she wears, and because posthumous depiction was not characteristic of sixteenth-century portraits, the sitter could hardly be Margaret (Davis, 1968, p. 92). By imposing the medical model on the painting, the analysis perpetuates the notion that disability is ahistorical and always manifested in certain physical characteristics.

Some scholars focus on the sitter's physical features, pointing out that Matsys has depicted a woman with Paget's disease, which causes bone malformation (opening quotation; Dequeker, 1989). The diagnosis openly applies the contemporary medical model. It might be correct, but it might not (Sharma, 1990). Regardless, Paget's disease was not named until the later nineteenth century, and so sixteenth-century viewers would not have associated this condition with the painting.

These interpretations may inform contemporary concerns in the separate disciplines of art, disability, or medicine. But their insights

apply present anachronistic thinking to a past work without acknowledging the assumptions which support these reappropriations. Such analyses shed little light on sixteenth-century disability and its artistic representations in their historical contexts. In contrast, my situated art historical/disability studies approach attempts to reconstruct how the portrait was received in its time. That reconstruction is based on considering the painting's form and content in light of available historical evidence. Although the Old Woman's representation follows the conventions of the municipal model, Matsys's rendering of them suggests that his aim was not to portray a disabled individual. From a sixteenth-century perspective, then, this is not a painting about disability.

Disability Studies and Sixteenth-Century Flanders

The term "disability," of course, is an English word which does not appear in written texts until the nineteenth century (Newman 2012, p. 9). The concept, however, has existed since at least recorded human history began. Any understanding of disability when Matsys was active must turn to the sixteenth-century Northern European culture as it transitioned between the High Middle Ages and agrarian, feudal ecclesiastical ideologies to those of the Early Modern period, which were more municipal and commercial.³

Sixteenth-century Northern perceptions of the body and disability were deeply rooted in the prevailing state of medical knowledge. Before certain scientific interventions were available, especially antibiotics and public sanitation, human populations were confronted daily with and/or sustained many more birth defects, rashes, fevers, infections, and other conditions than a contemporary Western individual.⁴ Given this everyday presence, a physical difference alone did not constitute a disability (Korhonen, 2014, pp. 30, 46). That concept of disability, associ-

ated with failure to meet cultural expectations, depended on other socioeconomic factors.

Prior to the sixteenth century, and lingering into it, high medieval church doctrine regulated socioeconomic matters in Northern Europe (Eyler, 2010, p. 3; Metzler, 2006, p. 13). Significantly, this spiritual doctrine hinged on physical appearances. From this perspective, an individual's state of moral and mental health, the essence of that person's life, was manifested through correspondences between outer behavior and appearances, on the one hand, and internal physical and moral states, on the other. Because this spiritual doctrine opposed body and soul, and the present and hereafter, a healthy bodily appearance represented a healthy soul and a person worthy of an afterlife in Heaven. An unhealthy body and its correspondingly unhealthy soul forecast an afterlife in Hell. In this environment, every human life began with the potential for physical and moral deviance and, perhaps inevitably, manifested it. Women's bodies, moreover, were considered inherently weaker than men's, physically and mentally. This significant difference aside, every believer's life goal was salvation, and salvation required perfection of body and soul. The church was responsible for guiding believers toward that perfected state (Eyler, 2010, p. 2; Metzler, 2006, p. 16-18; Stiker, 1999, pp. 65-89; Wheatley, 2002, pp. 194 ff.).⁵ Any earthly, physical attribute which might block an individual's way to salvation was a disability, and all humans implicitly shared this experience and the need to remediate it. For example, ascetics such as Hildegard of Bingen (1098–1179), Catherine of Siena (1347-1389), and Julian of Norwich (1342-1416), describe themselves as limited by their physical deficits. In so doing, they acknowledge their struggles to overcome their sinful, earthly nature and characterize their bodily pains as disabilities obstructing the path to Heaven (Newman, 2012, pp. 45 ff.). Edward Wheatley calls this Church-based concept of disability the religious model (Wheatley, 2010, p. 210).

Images created before the sixteenth century reflected this religious model of disability. Aimed at scaring sinners, these works portray the body, and disability, in terms of collective imperfection; the sinners' unhealthy bodies bespeak their unhealthy souls. This perspective is captured in a painting of a *Mystery Play* (1460) by Jean Fouquet (1420–1481) which represents sinners clamoring around the mouth of Hell.⁶ Hell is not only depicted as a distorted body part, the mouth from which deviant blasphemy emerges, but the individuals involved are also a correspondingly beastly collective. Their sinful bodies betray their disabled states of being.

The religious perspective retained a presence into the sixteenth century. Gradually, however, religious institutions and their collective worldview were overtaken by a municipal mindset concerned with individuals engaged in commercial or personal activities. This transition was facilitated and documented, as extant city records indicate, when the Church and city began sharing the burden of urban activities, thereby shifting their attention to occupational and bodily issues, for instance, rather than spiritual wounds (Farmer 2002; Wheatley 2002).

These municipal documents also chronicle how the printing revolution fostered secularization in sixteenth-century Northern Europe (Eisenstein, 2013.). In general, print technologies increased the availability of texts, the rate of literacy, and the dissemination of the texts and the values they espoused, all this to a more diverse readership. So too was the content of the texts more diverse. Many were published in the vernacular and addressed non-religious, moralizing subjects. The satires of Desiderius Erasmus (1466–1536) and Sebastian Brandt (1457–1521) especially encouraged readers to attend to their individual, present foolish lives. By drawing attention to the range of embarrassing, improper behaviors which humanity exhibits, these satires mocked the human race and called on each member to reflect on and attempt to avoid such ridiculous acts. Liberated from a sin-

gular concern with the future consequences of their collective sin, citizens could conceptualize themselves as individuals, a hallmark of early modernity (Coleman, 2002, pp. 2 ff.).⁷

Secular values also appeared in sixteenth-century art. In terms of this study, the shifts from religious and collective to secular and individualistic are salient with respect to portraiture. In Hugo van der Goes's (c. 1430/1440–1482) *Portinari Altarpiece* (c. 1475; Uffizi), the donors appear on separate side panels of the triptych; the husband, Tomasso Portinari, and two sons on the left and the wife, Maria di Francesco Barocelli, and daughter on the right. Smaller in scale than all other figures in the painting praying, they kneel in front of their respective patron saints and observe the nativity happening before them in the central panel. The placement of the donors, in the painting but to the side, as well as their diminished size, emphasizes their implicit participation in that central event; they do so in the present as but earthly sinners who aspire to one day enter Heaven. In the sixteenth century, attention turns to the patrons. The donor panels are excerpted, as it were, allowing the two individuals to be portrayed as real people in simple surroundings; the space might contain architectural or decorative items.⁸ Although the format retains the presence of the donors, the broader religious context and the third and central panel does not appear. Represented simply as paired portraits of couples, these small, private, domestic works were hung in homes rather than public churches. In fact, the tradition of the double portrait is associated with Matsys's many renditions of such works (Soussloff, 2002, p. 117).

In addition to new formats, increasing secularization led to new kinds of patrons and workshop practices. While fifteenth-century patrons consisted primarily of the wealthy (rulers, clergy, landowners), sixteenth-century patrons included middle class citizens, many of whom wanted and could afford to purchase private, domestic art.⁹ The different needs and incomes of these patrons could be met by assigning dif-

ferent tasks to artists based on ability and experience. Thereby, artists could be trained while the workshop produced more works in many sizes, formats, and media to meet the needs of these patrons (Silver, 1984, p. 116 & p. 143).

In this more secular environment, artists were better able to assert their status as independent creators, working for customers, rather than anonymous craftsmen, serving the one true Creator. Before the sixteenth century, for instance, few artists contradicted their collective identity by signing their works. By the sixteenth century, few artists hid their individual efforts in anonymity. This emerging sense of individuality is evident, too, in the development of new genres, notably, the self-portrait exemplified by Albrecht Dürer (1471–1528).

These socioeconomic developments affected how the body was conceptualized and represented.¹⁰ Although physical differences were still commonplace, they were increasingly framed in terms of the individual's ability to work. The practical reality of fulfilling present livelihood gained precedence over the spiritual matters of sin and salvation. Those who could not fulfill their socioeconomic obligations were effectively disabled.¹¹ I call this model of disability the municipal model and turn to Matsys's portrait to examine the model's presence in sixteenth-century Northern art.

Quentin Matsys and Art in Sixteenth-Century Flanders

Born in 1466 in Louvain, Quentin Matsys belonged to this transitional Netherlandish world and began his artistic activities there. In 1491, he moved to Antwerp, where he helped found its school of art.¹² By his death in 1529, his oeuvre comprised religious and secular paintings from his own hand and through collaboration with his workshop. These works were influenced primarily by Netherlandish painters of the previous generation such as Dirk Bouts (c. 1415–1475) and, at the same time, belonged to

the new sixteenth century, in particular, in their secular and Italianate elements.¹³

According to the current interpretations discussed above, Matsys's *Grotesque Old Woman* is an image of physical deviance and of the concept of disability. Yet, the medical model on which this understanding is based had not yet been conceptualized. Moreover, nothing in the picture indicates that the sitter was received as disabled. Closer inspection suggests, too, that this was not a painting about disability and physical defects, but about her life as a representative human being. Clearly, the painting has moved beyond the religious model of disability. But, does it represent the municipal model and how?

As indicated, the sitter, an aging woman, appears in an undefined space against a green background, and her only attributes are her body and costume. No decorative or religious elements are present. The portrait's non-religious content and format indicate that it originally belonged to a diptych, a standard domestic portrait of a middle-class or wealthy couple. To that end, the painting has been paired with several male portraits. These works are attributed to Matsys, represent men of a similar age as the woman, pose the men as the female sitter's mirror image, and, in the case of the paintings, are of comparable size.¹⁴ Together, facing each other, the paintings would have served the conventional purpose, decorating the couple's home. It seems unlikely that the couple commissioned a domestic portrait to mock the wife and characterize her as deformed. Instead, the portrait's diptych format and minimal contents suggest that it represents the woman in the spirit of the times, realistically, as a wife and, thus, in her appropriate social role. This assertion not only follows the municipal model then in place but again suggests that the painting's primary purpose did not involve disability.

Sixteenth-century written and visual imagery supports these assertions. First, despite the

lesser status accorded to women at that time, any physical differences did not prevent them from participating in civic matters, as wives and in other capacities. Women with missing or injured limbs, for example, were able to work and, in particular, to be wives (Newman, 2012, p.26). When women were characterized as disabled in texts and images, that designation most often dealt with deafness and/or inability to speak (Korhonen, 2104, p.33). Not surprisingly, disabilities were conferred along gendered lines. Sixteenth-century men typically acquired disability status when they were blind or blinded, a status which follows from the many men who lost their vision in industrial accidents associated with the textile industry (Farmer p.2; Wheatley, 2002; pp.194 ff.). Based on these conventions, the sitter can be interpreted as a working woman, rather than a disabled one.

Another of the painting's attributes, ugliness, was not considered inherently disabling in the sixteenth century for females or males. Instead, ugliness was connected with humanity more generally, as a manifestation of its inherent foolishness. Erasmus's *In Praise of Folly* (1511), mocks all humans for their ridiculous characteristics and behaviors, among them, being ugly or funny looking.¹⁵ He does not, however, use the language of developmental or intellectual disability. He makes clear that all humans are fools regardless of their bodily characteristics. In *The Flemish Kermis* (1566-69; Kunsthistorisches Museen, Austria), Peter Brueghel (c. 1525 –1569) depicts a motley group of peasants celebrating a wedding. Despite their bodily diversity, they were not considered disabled people, but rather foolish revelers pursuing leisure time activity. By extension, those who view the painting are also fools. Certainly, the sitter in the Matsys portrait is sexualized to the extent that her cleavage reveals her ample bosom, and she is hardly a conventional model of beauty. However, and in the spirit of Erasmus's work, these characteristics suggests that she is a rather typical woman for her time. She may be foolish by trying to appear younger than she is. But, for

that reason she is all the more human in this, her appropriate social role. Again, in sixteenth-century terms, the sitter is not represented as disabled.

The woman's costume supports this conclusion, suggesting specifically that she did not consider herself disabled in either the religious or municipal sense. True, her breasts are prominent, but that circumstance aligns with her portrayal as fool as well as with the sixteenth-century realistic portrait style. Additionally, the plunging neck line was popular in Europe at that time, perhaps giving feminine wives a somewhat positive spin (Murray, 2004). The presence of the sitter's cleavage, then, might well have been a fashion statement, one which portrayed her as a fashionable wife as befits her representation in a couple's portrait. The sitter's costume reflects other late fifteenth- to early sixteenth-century fashion trends followed by fashionable sixteenth-century Northern women (Laver, 1983, pp. 74 ff.). Both her lacy Italian hat and collar were popular at the time, the latter appearing no earlier than 1510 (Davis, 1968, p. 94). Although the sitter's fancy garb may provide a foil to her physical appearance, those clothes also represent her realistically as a fashionable woman, a foolish human but not a disabled one.

In sum, the available historical evidence indicates that Matsys's painting was created at a time when disability was represented in terms of the municipal model of disability. But, the woman's noteworthy physical variations do not automatically render her disabled in sixteenth-century terms. Rather than a painting of disability and deviance, the portrait is a conventional and very realistic picture of an individual and wife, someone able to serve her social role as fashionable wife and perhaps even laugh at herself, as a foolish human. As such, Matsys's portrait captures an environment in which ideas about the body were less constrained by Church doctrine and more by urban issues.

My analysis, of course, is speculative, as are some of those I critique. Additional research would help support my claims. Nevertheless, my combined disability studies/art historical methodology offers a fresh interpretation of the painting and the possibility of examining other art works in a similar light. Finally, the approach demonstrates how an interdisciplinary, historically situated model exposes the ways in which contemporary thinking all too readily locates disability in appearances. We should not assume that past people understood the world in such arbitrary terms. Doing so creates the impression that disability and abnormality are universals and inherent to humanity. Although we reject any past vocabularies that punish humans on the basis of arbitrary physical and gender variations, we can now benefit from other wisdom the past may offer, for example, when it suggests that we see beyond simple appearances and stop finding disability in perceived and arbitrary cultural norms.

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Image Credits

Figure 1: Quentin Matsys, *Grotesque Old Woman*, photograph courtesy of the National Gallery of Art, London.

Endnotes

¹My thanks to the National Gallery of Art, London, both to their research staff and their photography library, for their support in this project.

²This paper focuses on the Western tradition. I use the term "disability" when I refer to the concept. I use the terms "physical difference" to refer to describe attributes which are present and considered abnormal in a particular context. In so doing, I hope to maintain historical accuracy and acknowledge that human bodies do have similarities as well as differences; all of these may be visible but should not be judged in terms of abnormality.

³Because of space limitations, I have generalized a more complex story about the secularization process at this time. I do not mean to suggest the shifts I describe in any part of this paper were simple cause and effect, linear developments (Eisenstein).

⁴Obviously, physical differences are also apparent today; all humans face the possibility of disability, especially

as the average lifespan increases. But, the quality of the presence is certainly different than in the sixteenth century, for example because of the many assistive technologies now available.

⁵According to scripture, disability was not simply God's punishment for earthly sin, though certainly many people thought such thoughts, then as now.

⁶Location unknown, see <http://www.ecclsoc.org/mouthofhell.html>.

⁷A vast amount of scholarship addresses issues of identity and self (see Coleman et.al, 2002).

⁸Portraits of individuals were commissioned in the fifteenth century, primarily by the wealthy and clearly in smaller numbers than religious paintings which may contain donor portraits.

⁹Many kinds of decorative and practical art works were produced at this time and earlier, works which were not necessarily based on written literature and are now lost. These works and their perspectives on bodies and disability are beyond this paper's scope

¹⁰See note iv. Here, I necessarily condense a complex history of industrial development.

¹¹Korhonen (2014) holds this view and supports my argument in her work on sixteenth- and seventeenth-century humor.

¹² No guild records were kept prior to 1494 in Leuven. However, historians believe that Matsys was trained there because he never registered in Antwerp as an apprentice.

¹³ It is not clear if Italian influences came through direct contact or contact through his students, who included Joachim Patinir (c. 1480-1524; Silver, 1984).

¹⁴ Various drawings and painting are associated with the female portrait (M. Davis, 1968, p. 93), for example, a signed *Portrait of an Old Man* by Matsys (c.1517; Musée Jacquemart-André, Paris) and a drawing of an old man in a private collection (New York; Davies, 1968, pp. 92-5; Silver, 1984, pp. 220-1). None of these works has received any scholarly attention either in general or disability terms. Instead, they are simply listed in the catalogues of the collections to which they belong. The portrait of the Old Woman was believed to be based on a lost work by Leonardo da Vinci, but it is now believed that Matsys influenced Leonardo. (<http://www.theguardian.com/culture/2008/oct/11/art-paintingRenaissanceFaces:VanEycktoTitian>,

National Gallery, October 15-January 18). Although Panofsky argues that the painting was not a portrait but a satire (date of Panofsky, 1953 pp. 355-56), all available information indicates it was both (see below in text). Finally, the consensus is now that the painting is not a copy but the original by Matsys.

¹⁵ Not incidentally, Matsys knew Erasmus, having painted his portrait in 1517 (Galleria Nazionale d'Arte Antica, Rome; Campbell et. al, 1978; Gerlo, 1969).

Shifting Perception: Photographing Disabled People During the Civil Rights Era

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Abstract: During the American Civil Rights Era, photographic perception of disabled people shifted from constructs that empowered the abled “normal” to an empathetic awareness of social isolation and enfreakment. Through rhetorics of the stare, photographers demonstrated increased cognizance of what it meant to be an “other” in a society that valued homogeneity.

Key Words: art history, enfreakment, “other”

As civil rights garnered the attention of many in post-World War II America, notable photographers began to alter their visual rhetoric to embrace a more synesthetic view of disabled people. The resulting photographs addressed the social implications of what it meant to be perceived as different in a Cold War society that encouraged uniformity.

Although homogeneity was less a reality than a corporate-promoted and politically expedient perception, photographic representation in the years immediately following the war often embraced a widely accepted notion of what was considered normal. This exclusive, imagined community was comprised of able-bodied Caucasians who were financially secure and grateful for what their country had to offer. They were also accepting of, and comfortable with, their status in society. Those outside the norm, the “other,” were portrayed in ways that depended upon this imagined community’s predetermined conceptions or stereotypes. As the Civil Rights Era progressed, however, photographers began to bring awareness to the diminished status that had been attached to those considered outside this narrowly focused viewpoint based upon “normalcy.” Primarily through the visual rhetoric of the stare, these photographers drew attention to social isolation and enfreakment of

disabled people, rejecting traditional representations that had relied upon a psychological empowerment of the abled.

Normalizing the “Other”

Concern for the personal experience of the “other” in American photography revealed itself in many ways during the Civil Rights Era as awareness of individual perception increased and stereotyped viewpoints of those outside the corporate-promoted mainstream began to fall away. As American studies scholar James Guimond has demonstrated, the magazines *Life* and *Look*, by far the most prolific venues for photography in the 1940s, 50s and 60s, had blurred the lines between a mass consumer-oriented identity, conveyed largely through advertisements, and reality, thus contributing to a utopian vision of American life (Guimond, 1991). Referred to by sociologist Michael Schudson as “Capitalist Realism,” this national character was portrayed as eternally optimistic and homogenous and although it recognized the “other,” those outside of this imagined ideal community, it did so with a sense of benevolence, which largely avoided scenes of distinctive reality that might shock the viewer away from consumerist escapism (Schudson, 1984). Consider, for example, a goodwill advertisement from the summer of 1961 in *Life* magazine entitled “Dorothea Bendik keeps house for four from a wheel chair” (Dorothea Bendik, 1961, p. 8). Here a woman identified as having multiple sclerosis is portrayed seated at a dinner table within a meticulously kept middle-class home. Despite her disability, a sense of “normalcy” pervades the image. The implication is that through the benevolence of the General Electric Company, which has provided a specially designed room, her “otherness” has been removed and she has joined the ideal com-

munity. She tosses a salad while her husband carves a rather large ham, and their son looks on with anticipation. The framed photograph of Notre Dame Cathedral in the background implies that they are at least familiar with a broader culture. The comfortable lifestyle that capitalism provides is apparent throughout. She has been absorbed into the corporate-promoted mainstream of American society. The only reference to her status as “other” is in the presence of a portion of the wheelchair visible in the lower left of the photograph.

A more poignant and provocative representation of the “other,” in this case an African American, can be seen in Elliott Erwitt’s *Pittsburgh, Pennsylvania* from 1950 (fig. 1). Here the effectiveness of the image relies not upon absorption of the “other” into the “normal,” as in the image of Dorothea Bendik, but upon the normal viewer’s projection of stereotyped preconceptions onto the subject. An African American child smiles delightfully at the camera as he points a toy gun to his head in a gesture of mock suicide or perhaps Russian roulette. He stands directly in front of a tree, behind which is an inclined brick street so common in the surrounding ethnic neighborhoods of Pittsburgh. His clothes are outsized, perhaps hand-me-downs, and they fit loosely on his body as his shirt sleeves are rolled and his pants held up by suspenders. Paradoxically, the image is successful in that it presents a droll view of a child at play while inviting further contemplation concerning the collective plight of an oppressed minority. One might refer to the common reaction to this image as an uncomfortable amusement, a response often sought by Erwitt that plays upon our ability, based upon preconceptions, to, as he explained, laugh and cry alternately (Erwitt, 1988). This reaction is dependent upon a collective preconception of African Americans at the time, who

were often depicted in popular media as enduring their oppression with humility and humor. Well-known popular examples of this abiding character are actress Hattie McDaniel’s Mammy from the film, *Gone with the Wind* (1939) and the stereotypical roles portrayed by Dudley Dickerson on screen and television (Leff, 1999).

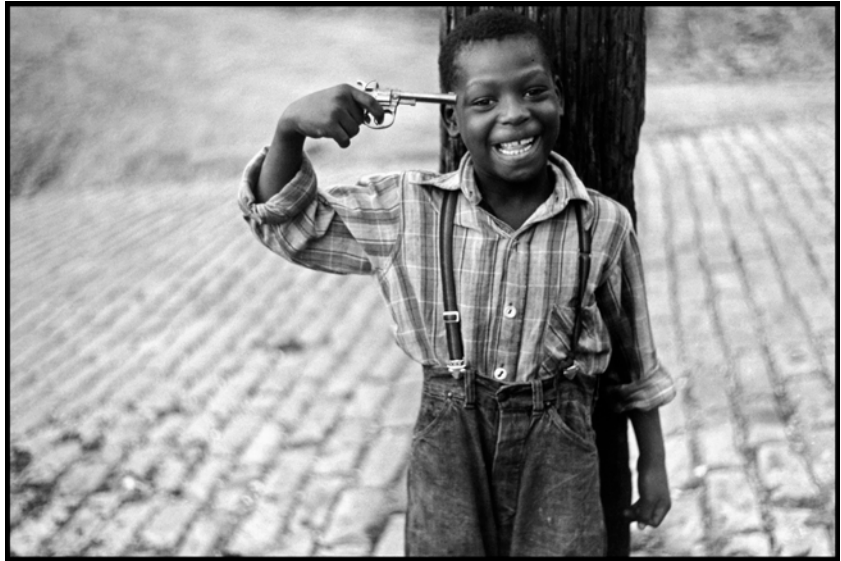


Figure 1

Erwitt’s image evokes mild shock while engendering sympathetic interest, as it embodies that distinct recognizable aspect of photographs that semiotician Roland Barthes has described as the “studium” (Barthes, 1981). Relying as it does on stereotyped preconceptions, however, Erwitt’s photograph is less dependent upon that second of Barthes’ photographic essentialities, the “punctum,” which is an element to which an individual viewer may relate personally. It lacks what art historian Erina Duganne has explored as intersubjectivity, a complex weave of photography, subject and viewer (Duganne, 2010). Erwitt’s image depends upon a common perception from a particularly narrow point of view. It is presented as a “fait accompli” in that it answers its own questions.

When Erwitt turned his camera to disabled people, he approached his subject with a similar expectation of the collective viewer’s perception of the “other.” In *Pittsburgh, Pennsylvania* (fig. 2), also taken in 1950, he relies upon a common

benevolent and colonial view of disabled people as remarkable individuals who overcome dissimilarity in pursuit of the normal. By equating the central figure, walking with what appears to be a perfectly normal gait on truncated legs, which extend only to just above the knee, with a more commonly encountered “normal” man who has the use of complete legs and feet, and who with apparent ease carries the added burden of a child in his arms, Erwit projects normality as a positive attainment, while strengthening the viewer’s own identity as “normal.” Mobility is reflected not only in the two walking figures who stand out sharply against the dark brick wall, but also in the aerodynamic lines and hood ornament of the front end of the automobile, which enters the scene from the right. Difference here is absorbed into the corporate myth of a homogenous American society, as disabled people figure becomes nearly indistinct from the every-



Figure 2

day “normal,” thus reinforcing a desirable monolithic perfection. He fulfills what disabilities studies scholar Rosemarie Garland-Thomson has referred to as the utopian fantasy of creating a perfect American society (Garland-Thomson, 2001, p. 364). Accepting disabled people man, who is clearly the exception rather than the rule, as “normal,” however, depends upon his embodiment within a collective idea of normalcy. His activity is thus framed within a traditional inspirational “struggle and accomplishment” rhetoric associated with disabled people “other,” thereby making him palatable and, for the viewer, self-affirming (Biklen, 1987, p. 81). Both inspiring wonder and affirming a common perception of reality, the image embodies two of the four visual rhetorics identified by Garland-Thomson as stereotypical ways of portraying disabled people (Garland-Thomson, 2001). While it invites the viewer to identify with the reality of the man’s ordinary activity

of walking, the photograph distinguishes him through the wondrous and extraordinary detail of his walking on truncated legs. Though this has the effect of bringing disabled people man into the “normal” world, it does so by reinforcing the ideal of the collective common. The desired attainment of a monolithic society has been achieved as disabled people “other” has been fixed and absorbed.

Rejecting this façade of a desirable monolithic society, while questioning the diminished status projected upon the “other,” photographer Robert Frank presented an America in which he saw very little homogeneity and which celebrated diversity in a way that ran counter to reinforcing the corporate view presented in magazines and other media outlets. As a Swiss immigrant, he abandoned the dependence upon a collective viewpoint by introducing an objective aesthetic that defied any one stereotypical read. *Canal Street – New Orleans*, 1955, for example, captures on a purely visual basis a diverse and varied group of people as they pass by the photographer’s lens on a crowded city sidewalk. Cropped at mid-waist and captured largely in profile, young and old, multiracial, tall and short, carefully shorn heads of hair and middle-aged balding ones all merge together in this image that captures the rhythmic dance of urban dwellers as they weave their way through

the crowd. Although he is enormously successful in conveying his perception of a society that is multifaceted, Frank presents the *other* as fact. His images generally lack the “haptic,” not in a traditional physical sense but in the expanded definition offered by cultural theorist Tina Campt as the way a photograph touches us in a synesthetic sense of extended associations of community and social relationships (Campt, 2012, pp. 43-45). One “sees” diversity in his photographs as one would see many different colors of fish in a fish tank; one does not “experience” it through one’s body by association, or for that matter through the bodies of those portrayed here. While Frank abandoned the stereotypical and common apparent in Erwit’s images, he also represented difference as ordinary – largely disregarding the experience of being an “other” in a society that values normality.

Affirming Difference

As the Civil Rights Movement expanded and increasingly drew attention to the experience of what it meant to be an oppressed “other” within a society that strove for and projected a common normality, photographers began to alter their visual rhetoric to consider a more synesthetic view that addressed the social implications of being perceived as different, thereby provoking a perception beyond the narrowly focused common viewpoint of what is “normal.” As with the photographs we have examined, that provocation was predicated upon a viewer’s preconceived notions; however, the preconception now emphasized individual experience rather than a collective commonality and stereotyped “other.” Affirming Barthes’ contention that photographic poignancy is overwhelmingly brought by the viewer’s previous experience, these images prompt under-

standing by relying upon sympathetic reactions (Barthes, 1981). Moreover, the increased reliance on individuality contributed to the viewer’s further understanding of the limited value of framing the “other” within a broad stereotype identification.

In *Los Angeles*, 1969 by Garry Winogrand (fig. 3), the socially objectionable, and thereby salient, activity of staring demarcates the abled from disabled people. In the center of the image are positioned three conventionally attractive women who walk along Hollywood Boulevard toward the camera; the sidewalk stars from the Walk of Fame visible underneath their feet enhance the impression that they are indeed the ideal attainment in a society that values youthful conformity in physical appearance. Their healthy legs are emphasized both by the short, fashionable skirts that reveal them and the exaggerated shadows they cast in front of the women. The lead figure stares intently to her right at a man in a wheelchair. Unlike the three women, who walk easily within a sun-filled world, the disabled figure sits in shadow, slumped over in his chair, barely able to hold himself erect. The cup that sits between his legs for alms is in direct contrast to the bulging purse carried by the staring woman.



Figure 3

Staring, as Garland-Thomson has pointed out, is an activity that contributes to a form of exclusion from an “imagined community” (Garland-Thomson, 2001). In this instance it also reinforces a societal hierarchy important to Winogrand’s work in the 1960s, as it validates and enhances his emphasis on the young and conventionally attractive female as “normal” by contrasting her with an outsider, an “other.” Considered within this context, disability studies scholar David Hevey’s contention that Winogrand contributes to the enfreakment of disabled people through an asymmetrical disharmony is significant as segregation from the ideal normal is certainly implied if not stated directly (Hevey, 1992). Embodied in this separation, however, is a street photography directness that contributes to our understanding of the individual experience of “being” the outsider, in this case disabled people, rather than relies upon stereotypical preconceptions—for as it distinguishes through staring, and through formal considerations such as dramatic lighting and composition, it also presents in a very poignant way social isolation, addressing what it means to be singled out as an “other.” Staring makes us question, reconsider, and challenge our preconceived notions. It is, as Garland-Thomson considered, a form of empathetic communication through visual engagement that can also lead to understanding (Garland-Thomson, 2009).

A similar approach to segregation is apparent in Winogrand’s *London* from 1967 (fig. 4). Less concerned with enhancing his view of female attractiveness through contrast, Winogrand here provides a more direct reference to social and physical isolation. As she crosses the street, a young woman wearing leg braces carefully steadies her crutches, shifting her weight from her legs to her arms with considerable effort. Her right hand desperately holds onto

packages while grasping a crutch. The physical strain on her body is evident as she manipulates it across the street; her gait is awkward though calculated, intentional and deliberate. In contrast, the gait of those around her is rhythmic and graceful. They place one foot in front of the other without much thought as the posterior leg easily holds the weight of the body while projecting it forward. The fluidity of their walk is intuitive, so much so that their upper bodies give little indication of the remarkable ac-



Figure 4

complishment of their legs. One woman engages in animated conversation, raising her right arm and extending a finger as if to emphasize a point, while her left hand nimbly holds a handbag and child’s jacket while gripping a small change purse between her fingers. To her right a woman listens attentively while holding the hand of a child who walks in unison with her. Following closely behind is another child. Both children walk forward without much thought as they stare off to their right at the woman using crutches. Their stares do not disrupt their progress forward as they continue to make their way across the street. The same can be said of the businessman and the porter behind the children, who also stare at disabled people woman. Amplified by the stare, the contrast between the woman with crutches and those around her is stunning.

As anyone with a disability can attest, staring is commonplace among children when confronted with an unrecognizable experience, and so Winogrand's capturing of such might not be considered unusual. His unique approach, however, embodies an enlightened view of the personal and social implications of the stare that moves beyond more traditional and acceptable forms of staring at disabled people. These conventional practices of staring often took the form of self-aggrandizing admiration, sentimentality or benevolence (Garland-Thomson, 2001). Winogrand's photograph belies these by conveying in very real terms the social isolation and separation that occurs when one lives as an "other."

Shifting Perception Through the Stare

Concern for the personal experience of the "other" became more prevalent in American society as perception shifted from a mass corporate-inspired perception of those considered outside the ideal community and therefore less than, toward a view of how the "other" experiences, and ultimately perceives, that perception. Ralph Ellison's novel the *Invisible Man* (1952) and John Howard Griffin's journalistic *Black Like Me* (1961) are just a few examples of noteworthy works that addressed the experience of being seen in terms of a collective "other" without regard to the feelings and complications attending the individual. Griffin, a white man of European descent who chemically altered his skin to appear African American, described his visceral reaction to the "hate stare," an indiscriminate superiority response he encountered among some whites based upon the color of his skin (Griffin, 2011/1961). In Ellison's prologue, his main character, an African American, proclaims his frustration at being seen only through preconceptions, rendering his true identity invisible (Ellison, 1995/1952).

Ellison's struggle to move beyond this invisibility through his writing, to get at the indi-

vidual behind the predetermined meaning, is analogous to his interest, both metaphorically and in reality, in photography. As literary and visual culture scholar Sara Blair has suggested, Ellison was aware of the photograph's tendency to substantiate popular myths and assumptions about African Americans (Blair, 2007). In addition to his own work in portraiture and commercial photography, Ellison collaborated with fellow African American photographer and writer Gordon Parks on a photojournalistic essay concerning the people in Harlem, writing out a shooting script for Parks that emphasized extreme angles to convey psychological dispossession (Jackson, 2002). Ironically, by his own admission, Ellison's experience with the camera allowed him to hide his true identity while revealing that of the subject. In the single photograph we have extant from Ellison's notes for *The Invisible Man*, however, invisibility is substantiated through an implied stare. Lying on the pavement is an anonymous middle-aged woman; she is immobile, presumably unconscious, but her situation is not known to us. It is a cold day, judging from her winter clothing and that of the surrounding figures. Her weathered face has a peaceful expression on it, as though she were sleeping. Her left arm is raised to hold the collar of her coat close to her body to keep warm. We see only the upper portion of her body, jutting in from the right side of the photograph. On either side of her, two officers stand passively. The viewer sees only the lower half of the legs of one and the arm and coat of the other, but through the position of their bodies, their unseeing gaze is implied.

Within the realm of disability, the most poignant reflection on what it means to be an "other" was psychologist Beatrice A. Wright's *Physical Disability – A Psychological Approach* (1960), where she presented a detailed clinical analysis of how disabled people respond to being stared at and other manifestations related to the distinct experience of being outside the ordinary. Her intention – to aid in the socio-psychological rehabilitation of disabled people – is noteworthy

because of its focus on the perception of those on the receiving end of the real and metaphorical stare and subsequent social isolation. She also pointed out the unique problems encountered by disabled people that differ from those experienced by other minority groups, including the lack of a shared community and subsequent feelings of inferiority that can lead to disabled people idolizing the so-called “normal” (Wright, 1960).

The discussion concerning how “others” perceive a narrowly defined, predetermined perception of them is particularly relevant to the photograph, because the reaction to the image is dependent upon the viewer’s previous experience. As philosopher Jean-Paul Sartre noted, objects in a photograph only become meaningful signs when the mind transforms them into representative matter; thus comprehension of an image is based upon none other than past comprehensions (Sartre, 2004/1940). As Barthes reiterated in *Camera Lucida*, the reaction to a photograph is overwhelmingly brought by the viewer (Barthes, 1981). Succinctly put, when one encounters a photograph one searches for a reference point within one’s realm of experience in order to give it meaning. This activity is heightened by the photograph’s inherent verity, or at least the belief (less so now but still true) that a photograph captures a moment and holds it still against time, catalogs it for future use.

Reading images of disabled people presents a particular conundrum for the average viewer because reference points, that from which one determines meaning, are often outside the realm of bodily experience from which, as phenomenologist Maurice Merleau-Ponty posited, one derives one’s view of the world (Merleau-Ponty, 2012/1945). As we have seen, previous images of “others” provided that reference by alluding to a collective, and often stereotypical, viewpoint. Capturing the stare, however, replaces that collective view with a more personal and individualistic bodily experience, one of a prolonged search for a reference point that is largely

missing from past comprehensions. In Winogrand’s *Los Angeles* (fig. 3), the stare was effective in conveying this search but couched within conventions of beauty and abnormality. Capturing the staring of children in *London* (fig. 4) evokes a certain innocence that we can associate with our own lack of reference because children have less bodily experience from which to draw meaning. Conversely, or one might even say perversely, a photograph of disabled people and accompanying stare, however socially unacceptable, provides a reference point that enhances our understanding of the experience of being the object of the stare – the “other.”

Photographs provide the means for a socially acceptable form of staring – one may look at a photograph intently, searching for meaning, without social consequences. Diane Arbus, in her straightforward photographs of people, not only provoked the stare, but aggressively invited its continuation through a prolonged search for meaning. In *Woman with Bangs, N.Y.C.* (1961), for example, Arbus captured what upon first glance would be considered a quite “normal” person within the recognizable realm of bodily experience. She is dressed for her own comfort, warmly in clothes that are suitable for walking in cold weather. But she is also dressed for someone else, for others in society who might see her. She wears a hat that serves no practical purpose, and her collar is open to reveal a string of beads that serves as cultural decoration along with her blouse, suit and large button. Her purse is haute couture, or at least a knock-off that resembles such, and it dangles from her left gloved hand, which also holds a change purse and the glove from her bare right hand that holds a lit cigarette between two fingers. All of these signs are comprehended because they are within the viewer’s realm of bodily experience, and thus reference points are provided. The viewer presumably has experienced cold and subsequent attempts to stay warm and recognizes, therefore, coats and gloves. One also experiences the need to carry things and has seen bags that are as much about fashion as they are about utility.

The viewer, particularly in 1961, would have experienced the burning embers and smell of a lit cigarette. These are all mildly interesting and provide what Barthes would refer to as the “stadium” – a collection of easily recognizable data. What makes Arbus’s photograph so intriguing, however, is that she does not leave the viewer there. She seeks a prolonged stare by inviting interpretation beyond the commonplace and perhaps beyond the viewer’s realm of reference. She accomplishes this through a confrontational approach where the woman stares at the camera and, by extension, the viewer. The viewer stares back. The uncomfortable feeling of the activity were it to happen in reality is mediated by the photographic process—on the part of the woman, the camera itself and on the part of the viewer, the photograph. In addition, the intense and prolonged stare is encouraged by the title, which directs the viewer to the woman’s short bangs and from there an awareness of the heavy makeup and overt attempt at symmetry to cover up the lines of experience that derive from a life lived.

When Arbus turned her lens to disabled people, to those clearly labeled as “other,” she often did so by contextualizing the unusual within the ordinary and relating it to the viewer with the visual rhetorical device of the stare. In *Jewish Giant at Home with His Parents in the Bronx, NY* (1970) Arbus placed Eddie Carmel, a man whose condition of acromegaly led to his unusually large size, leaning on a cane and stooping in his apartment next to his parents, who stare up in what appears to be amazement and wonder at their oversized son (Millett-Gallant, 2010). Nothing within the image seems out of the ordinary, except the large man who is the object of his parents’ stare. In fact, the setting and the mother and father are, one might say, remarkably ordinary. His father wears a suit and his mother a housedress, and judging by the furniture and their distance from the ceiling they seem of common height and their surroundings suitable for their stature. Nothing appears out of place except the “Jewish Giant,” who, lit up

by a strobe, towers over his parents and stoops to fit in this unsuitable environment that has been created for the so-called normal (Millett-Gallant, 2010).

As with *Woman with Bangs*, the title directs us to a narrative content, essentially telling us, as writer and curator Judith Goldman pointed out, how to read the image (Goldman, 1974). Our true comprehension, however, is based primarily upon the stare, which leads us to perceive the extraordinary through the ordinary. Although he is enfreaked, as art historian Ann Millett-Gallant has explained, by virtue of his parents’ stare, he is also brought into a realm of comfortable comprehension (Millett-Gallant, 2010). Because of their privileged relationship, and his comfort in staring back, the social taboo against staring is nullified. It is through the parents’ astonished but socially acceptable gaze that the viewer is likewise given permission to stare and thus begins to understand Mr. Carmel’s perception of a life in which even his parents have marked him as a distinctive “other.”

As Hevey argued, Arbus brought disabled people into a “non-disabled” world view, but did so through spectacle and enfreakment (Hevey, 1992). Her significant innovation, however, was to place the “other,” the enfreaked, within a context that began to approximate the viewer’s bodily experience, primarily through the stare. This approach is analogous to that accomplished earlier in her images of a nudist camp. *Retired Man and His Wife at Home in a Nudist Camp One Morning, N. J.* (1963) captures a familiar setting complete with chair, couch, rug, and television—all materials for which the common viewer has a reference—inhabited by a seemingly ordinary couple who become extraordinary by virtue of the fact that they are completely nude except for shoes on their feet. The viewer is invited to stare at the spectacle, one of the great strengths of Arbus’s photographs; but by bringing them into one’s frame of reference, through a recognizable setting, one is provided a measure of comprehension beyond stereotype. This

interpretation contradicts somewhat humanist and cultural critic Susan Sontag's contention that Arbus's work does not invite viewers to identify for it reminds the viewer that humanity is not one (Sontag, 1990/1977, p. 32). Indeed, rather than appeal to a compassion based upon preconceived stereotypes, Arbus brought the unique individual into familiarity.

While approximating the bodily experience of what it means to be an "other," to give us some intimation of being outside the boundaries of what is considered normalcy through contrast with the ordinary, Arbus also conveyed the absurdity of the attempt. Though in her work the "other's" perception becomes comprehensible, the "other" as being can never fully become part of the collective normative for the primary means of identification remain salient. *In Masked Woman in a Wheelchair, Pa.* (1970) a woman in a wheelchair holds a Halloween mask up to her face. She is shown completely, nearly in profile in front of a street curb, sidewalk and brick institutional building. It is an early autumn day and her legs are covered with a blanket to keep them warm while in a stationary position. Bright sunlight filters through the tree branches defining the few leaves that have fallen to the ground and glistening off of the metal rims and spokes of the wheel of the wheelchair. Generally used among the common to transform or hide one's identity, the mask here becomes a useless instrument – a fallacy, for the wheelchair, prominently lit and displayed from the side, remains the most salient characteristic of her identity. She will forever remain an "other." Despite the intense stare the photograph affords the viewer, actual bodily experience remains beyond grasp. There is a profound dichotomy here, for although the photograph contributes to the viewer's understanding of the disabled "other," the longer one stares, the more one is met with silence – like Ellison's character in *The Invisible Man*, the object of one's stare is yet invisible.

These photographs demonstrate a shift in perception of disabled people as the Civil Rights Era progressed and increasing awareness of the implications of being different in a perceived ideal homogenous society emerged. Largely through the rhetoric of the stare, innovative photographers began to address the complex nature of being disabled within a projected utopian environment based upon the "normal." By rejecting preconceived stereotypical reference points, which served to reassure the "normal" of their privileged status, photographers began to embrace a more nuanced representation of what it meant to exist outside of the norm. Far from proposing solutions to the accompanying social isolation, these photographers nonetheless enhanced our understanding of what it meant to be a disabled "other."

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Image Credits

Figure 1 - Elliott Erwitt, Pittsburgh, Pennsylvania, 1950. © Elliott Erwitt/Magnum Photos, New York, New York

Figure 2 - Elliott Erwitt, Pittsburgh, Pennsylvania, 1950. © Elliott Erwitt/Magnum Photos, New York, New York

Figure 3 - Garry Winogrand, Los Angeles, 1969. © The Estate of Garry Winogrand, courtesy Fraenkel Gallery, San Francisco, CA.

Figure 4 - Garry Winogrand, London, 1967. © The Estate of Garry Winogrand, courtesy Fraenkel Gallery, San Francisco, CA.

no answers to these questions on the next pages. For example, on the next double page (fig. 2), which has a rather rigid structure of 79 panels, the observer is confronted with the female character's everyday activities: getting up, showering, dressing, and shopping in the supermarket. Her physical disability – she is wearing a prosthesis on her shortened left leg – is only hinted at on the first pages: when showering, she stabilizes with the help of the handle on the stool in the bath tub, and outside her flat she uses a cane. A

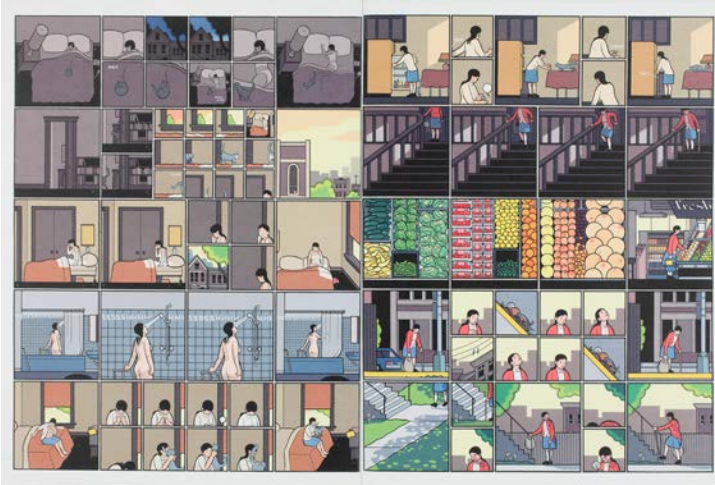


Figure 2

sequence of four panels (fig. 3, detail), showing the first paths down the staircase after she locks the door, points at her disability, because she stops on every step with both feet. Only after several pages is the protagonist shown lying on her bed without her artificial leg, which confirms earlier suspicions.

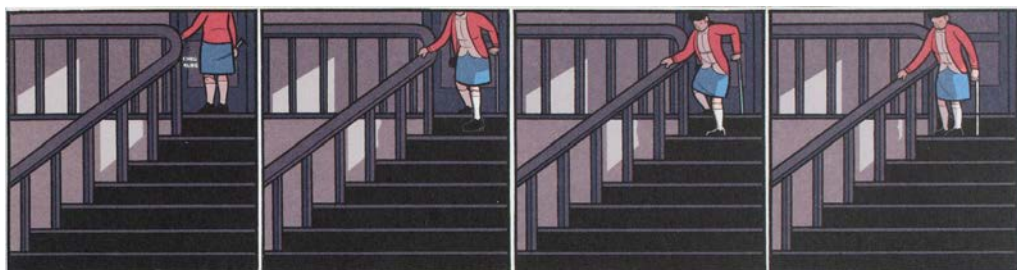


Figure 3

Ware uses the diagrammatic structure in the beginning as exposition the way it is used in drama in preparation to the plot. This exposition provides an emotionally intensive, as well as intellectually demanding, insight into the world of the character. The diagrammatic structure has a relevant consequence on the following pages;

it depicts rituals of everyday life in a sad shade full of isolation and loneliness. The protagonist's physical disability does not obviously play an important role in this, since it is neither mentioned nor shown in the diagrammatic structure or the introduction of the protagonist's everyday life.

Only In Conjunction with Others

Within the story, the protagonist's disability is only associated with human relations. When she is working as a nanny in a foreign family, the father of Jeff – her fosterling – explains the reasons for her employment: “Well, we just hoped that in your case, you know, he might not... get so, uh... attached...”⁴ In this context “attached” has to be interpreted in two senses: physically, as the boy begins to discover his sexuality, but also emotionally, as he is more intensively tied to her than to his mother. The father assumes that the protagonist's physical disability would prevent Jeff tying himself too much to the nanny. When this happens, nevertheless she is fired. The protagonist is confronted with prejudices such as sexual unattractiveness, which may be seen as negative associations with disability. Within the story, physical

disability is addressed and identified as a deviation from the norm by other characters, not by the protagonist herself. The judging of disability through others has a substantial similarity in the relation of the reader-observer to the protagonist: the interpretation of her disability is also left to others - that is to say to the reading observer. On the perception level, a connection be-

tween the protagonist's despair and her physical appearance seems likely when her shortened leg is interpreted as limitation by Jeff's father. In the way of arranging the story in the hybrid medium comic, Ware doesn't force this interpretation on the observer – at least no more than the opposite interpretation that physical disability does not play a dominant role at all. The construction of meaning is left to the reading observer.

Ware brings across this frankness and ambiguity using images. Images cannot offhand be subjected to preconceived schemata as they possess their own surplus value that cannot be translated into or expressed by language (Imdahl, 1980, 93; Siebers, 2009, 76–77; Boehm, 2007, 34–35). This leads to an ambiguity of images and, in principle, to a never ending process of perception: images have no beginning and no decided ending. A new examination of an image can lead to the discovery of new aspects. Given the example of the diagrammatical structure, this means that reading and observing don't end once all parts of the image and text are perceived. They have to relate to the entire diagrammatical structure and its details. Simultaneous (conceiving the entire image) and gradual (focusing on separate details) effects are irresolvably and mutually linked when an image is observed (Imdahl, 1994, 310). This nature of images turns the process of perception into a highly complex operation. Literature and disability studies scholar Tobin Siebers (2009, 87) adds a physical dimension to these reflections based on image theory. According to him, human beings relate their actions and interactions to their physical condition. Moreover, the socially constructed norm of an ideal body is connected to its physical condition. Splitting the body in two-part opposites (like normal/abnormal, perfect/imperfect) puts the body into context with those of others and ultimately into context with a preconceived notion of an ideal body (Davis, 1997, 53–54). Creating categories of binary opposites governs everyday perceptions, be it of a more attractive man or woman on the way to work or when looking at ads; the

body is always in a state of comparison with others. In Ware's comic, these mechanisms of body classification also work on a subconscious level.

Completing Mentally

Artist Marc Quinn also uses this fundamental human disposition of comparison and rating in interactions with others and perception of self and others. In his series of sculptures *The Complete Marbles*, he is explicitly analyzing the norms originating from cultural and social contexts. The sculpture *Stuart Penn* (2000, fig. 4) is made of marble, a traditional material of fine arts associated with nobility, beauty and heroism. The sculpture shows a male figure standing on its left foot. Its right leg is lifted into the air in a powerful stretch; its head turns in the direction of the lifted leg, and its trunk stretches diagonally. The sculpture is performing a movement known from various martial arts. Although typical features of this movement, i.e.



Figure 4

the painfully stretched foot and leg, are shown only as a shortened limb, an observer may complete the alleged “missing” parts and imagine the movement performed by a standardized or even idealized body.

How does this work? The answer is to be found in the cultural background of the observer concerning the representation of idealized human bodies in sculptures such as those of classical antiquity – e.g. the *Venus de Milo* (c. 100 BC). Typically classical sculptures survive as torsos, i.e. without limbs. Disability studies scholar Lennard J. Davis (1997, 56–57) points out that contemporary art historians especially are not able to conceive the constitution of a sculpture with missing limbs and that they want to add the missing parts. With psychoanalyst Darian Leader (2000, 16) I want to bring forward the argument that adding missing limbs is part of our socio-cultural imprint, regardless of whether one has a profound knowledge of art history or not. The title *The Complete Marbles*



Figure 5

shows clearly that Quinn is aware of this fact: by using the adjective “complete,” his marble sculptures are compared to classical “incomplete” ones. At close sight the observer can see that the sculptures are elaborated to the last detail. The artist deliberately uses this perfectionist elaboration in order to challenge the first impression of an incomplete sculpture and to point out the observer’s own bias. This is supported by the choice of titles for the individual sculptures in the series. The sculpted figures refer to the human model by using their first and family name, as a means of relating to its contemporary reference. The *Venus de Milo*, the goddess of love, instead lays claim to a more objective presentation of transcendence and Deity.

Another sculpture that can be associated with the series is *Alison Lapper Pregnant*. The temporary installation of the sculpture (fig. 5) in 2005 on the Fourth Plinth⁵ of Trafalgar Square, one of the most busy locations in London, offered Quinn the possibility to make “stereotypes of and assumptions about disability visible and open for public debate” (Millett-Gallant, 2000, 53). The larger-than-life-size sculpture shows eight-months-pregnant artist Alison Lapper, who was born with short legs and without arms. The installation of the sculpture in a highly frequented location fuels an ongoing controversy concerning observers’ socio-cultural notions of disability. On the one hand, *Alison Lapper* is stylized into a heroine among the heroes of Trafalgar Square; on the other hand and to the same extent, Quinn is accused by critics in public debates of displaying a lack of taste and of exploiting a disabled person for the shock factor (Quinn, 2006, articles and comments by Members of the Public, n. p.; Millett-Gallant, 2000, 61–62, 67–68). Art historian and cinema studies scholar Julie Joy Clarke (2008, p. 1) argues that although contemporary artists and film makers contribute to the improvement of the image of disabled female figures by representing them in works of art, these females are still portrayed both as abnormal and monstrous. Clarke describes *Alison Lapper Pregnant* on the Fourth

Plinth as “monstrous-gigantic” (2008, p. 7) because of her size. This statement is only valid when ignoring the dimensions of the square as well as the size of the Fourth Plinth in comparison to human dimensions. Had the sculpture been presented in real-life proportions like it has been shown since 2000 in exhibitions at galleries and museums, the installation would never have had the attention and resulting controversy about the representation of disability in a highly frequented location. Quinn proportionally adjusts the size of *Alison Lapper Pregnant* to the size of the Fourth Plinth, which makes the pregnant woman equal to the rest of the sculptures on Trafalgar Square. This change of scale triggers questions of gender, sex, disability and heroism.

These works of art demonstrate that in a social and public context, disability is still struggling with negative connotations. Social sciences and disability studies scholars Tanya Titchkosky and Rod Michalko (2012, p. 127) call this fact the “disability-as-problem frame.” The basis of the phenomenological approach of Titchkosky and Michalko is the assumption that we perceive the world from our own point of view with certain expectations and valuations. Social sciences and disability studies scholar Markus Dederich (2007, p. 80) points out that in this context, bodies express meaning. With regard to disability, this implies that deviations from the norm, i.e. physical otherness, may result in uneasiness, and lead to prejudice. This disregard is a symptom of the “frames,” the social and cultural conditions that provide a reference system for human interaction, described by Titchkovsky and Michalko (2012, p. 129), which are not in the open and not discernible in everyday life, but have to be disclosed by self-reflection and critical examination. Works of art can help to reflect the mechanisms of bias, as I have shown with the two aforementioned examples of Quinn’s sculptures. The observer puts Quinn’s sculptures into context with classical statues, thereby adding the “missing” limbs in his/her imagination and reflecting on this biased attitude. Ware uses a similar strategy in *ANL no. 18*; the reading ob-

server is confronted with the biased attitude of other characters within the story with respect to the protagonist’s disability and therefore has to think about his/her own interpretation: whether the observer (subconsciously) holds the protagonist’s disability responsible for her loneliness and death wish or not. Thus the observer becomes aware of his/her own socio-cultural imprint. He/she is forced to challenge his/her biased position caused by restrictions of society. These examples reveal that a thorough confrontation with works of art helps to make the recipient aware of his or her own bias.

Connotation of Prosthesis

An important element in *ANL no. 18* that confronts the reading observer once and again with his/her own prejudice is the protagonist’s various prostheses. When shaving her legs in the bath tub, the main character remembers a situation on the train (fig. 6): a young woman opposite had called her partner’s attention to the



Figure 6

prosthesis. Sitting in her bath tub, the protagonist is not pleased about such incidents: “What do they really mean, anyway: ‘my’ leg? Of course it’s mine... just the same way those were ‘her’ shoes or ‘her’ purse or ‘her’ stupid boyfriend with his stupid pointy sideburns.” And two panels further: “Anyway, I’ve had six legs now total... people don’t realize it, but when your body changes, the prosthesis have to change, too...” In nearly every panel in this bath tub episode, the prosthesis is addressed in the protagonist’s thought bubbles. Consequently, the reading observer on the one hand gets to know the frustration about the staring and the ill-considered statement. On the other hand, he/she is confronted straightforwardly with information not previously considered (“people don’t realize it”). On the visual level the reading observer experiences two different ways of observing. The observer is deliberately denied a glimpse of the protagonist’s face, as she visually withdraws herself from the observer’s gaze, whereas she allows a deep look into her inner world, her frustration, on the textual level. In the third panel, the reading observer assumes the protagonist’s point of view and is confronted with the staring looks of the people sitting opposite. On the visual level this refers to the considerations and statements that follow. Increasing exposure to and the denial of the gaze as well as staring on this page reveal a fundamental problem, which very often defines the relationship between individuals with and without disability.

According to women’s and disability studies scholar Rosemarie Garland-Thomson (2000, p. 335), the staring of non-disabled individuals initiates very often mechanisms of power and control towards disabled people, as disability is being characterized by the piercing look as deviation from the standard norm and as otherness. The process of staring is in fact not unilateral, as the stared-at person is by her reaction contributing to this “complex process of social choreography between two individuals” (Garland-Thomson, 2006, p. 180). The bathroom situation illustrates quite clearly Garland-Thomson’s

reflections: the reading observer, who can quite radically exercise power by choosing the speed of turning pages, is not able to totally control the protagonist with his/her stare when she is shaving her legs. Although her short leg has a prominent position in some panels, her face is not even shown once on the whole page. As the face is an extremely important element in immediate intellectual and emotional communication, the observing reader has to overcome his/her frustration at being prevented from direct access.⁶ On the other hand, there is the panel where the reading observer assumes the protagonist’s perspective and is instead exposed to the staring eyes of the young couple. Thus the reading observer experiences both sides of the interaction of staring. To the protagonist, her prosthesis is much like her clothing or accessories and therefore a natural element of appearance in everyday and public life. To her, the prosthesis has a deeper meaning than the prejudiced view from outside (“That’s not really her leg”) suggests.

Prostheses are also of importance in some scenes in Matthew Barney’s film *Cremaster 3*⁷ (2002). Aimee Mullins, a professional athlete and model whose legs were both amputated, plays several roles in that film, for example the character “Oonagh” who is part of a mythical story, as well as the role of a female character who is able to cut potatoes with blades under her shoes. The following refers to a small part of the film, the interlude *The Order*, to emphasize Barney’s special interest in Mullins’s prostheses. The Order is a sort of game show set in the Solomon R. Guggenheim Museum in New York where the male protagonist “Entered Apprentice,” played by Barney himself, has to succeed on five levels – similar to the initiation ritual of the Freemasons.⁸ On the third level the “Entered Apprentice” faces the female figure, here called the “Entered Novitiate,”⁹ who is wearing a white apron, long gloves and white headdress. She is also wearing transparent prostheses with high heels. The special shape and the transparent material of the prostheses draw attention to

their sculptural qualities. Moreover, they open a perspective on the two leg stumps ending right under her knees. The female figure moves to and fro on a line with a slightly unstable gait until she faces the “Entered Apprentice.” As they walk towards each other, the protagonist is suddenly wearing the same outfit as the female figure, with a white apron and high heels. When they meet in the middle, they virtually merge into one another before the female figure bites into the male’s shoulder. Thereafter the female figure transforms into a hybrid creature with the limbs of a cheetah and the upper body of a woman.¹⁰ A violent struggle between the protagonist and the creature begins. The half-human creature chases the protagonist until he brutally kills it. This short act of fusion, and the fight that follows, point to the protagonist’s fight with his lower ego, which he has to kill in a Masonic ritual in order to refine his self (Wruck, 2014, 96). The “Entered Novitiate” and the “Entered Apprentice” are two parts of the same figure which, for a short moment, is reflected by the two characters wearing the same outfit, even the transparent shoes with heels.

In contrast to “Entered Novitiate,” the transition between leg and prosthesis of the creature-woman is hidden by the cheetah-spots and by the form of the cheetah-legs. The “Entered Novitiate” transforms entirely into a hybrid creature with strangely formed legs. Both figures are biographically and thematically related to the actress Mullins. Her way of walking as “Entered Novitiate,” with striking prostheses, can be linked to her career as a model on catwalks.¹¹ As the cheetah-woman, she is wearing prostheses that are more related to her sporting career. Prostheses for athletes with amputated legs are made of carbon fiber and imitate the leg form of cheetahs. It seems like an ironic exaggeration that the professional sportswoman is being transformed into the animal, which was the inspiration of such costly prostheses for professional athletes. Clarke also examines this example from *The Order* concerning the representation of female monstrosity. She emphasizes

the relation of the two figures, the woman in white apron and the cheetah woman, to the actress Mullins when writing: “Images of Mullins in Crewmaster [sic] tend to feminize her in extremely stereotypical ways – woman as monstrous cyborg, woman as *femme fatale*, woman as cat-like creature. Her deviant body appears to reflect her polymorphous sexuality” (Clarke, 2008, 9). Clarke’s argument is nearly exclusively focused on the actress. I want to offer a different interpretation that is more interested in the narrative context. The stereotypical interpretation put forward by Clarke is qualified by the scene of the two figures becoming one before the fight with the lower ego: man and woman are identified as two sides of the same figure that belong together but are fighting each other at the same time. This is not a matter of questioning the erotic aspect of Mullins’s figures Clarke mentions in the cited phrase. But in my opinion Clarke’s argument about the exposition of female disability and the therewith related transformation into monstrosity should be put into perspective: in fact, the actress Mullins gives Barney the chance to visualize processes of transformation.¹² The decisive factor in *The Order* is not Mullins’s negatively connoted disability, but the potential of her ability to transform and the versatility in the use of prostheses, which have immense sculptural qualities. The leg prosthesis is presented positively as means of sculptural design and – from the cinematographic point of view – as an increase in possibilities to visualize processes of transformation. This exposing of the potentiality of prostheses in *The Order* requires an understanding of the relationship between wearer and to-be-worn, similar to *ANL no. 18*, in which the protagonist puts it consistently in the mind of the reading observer: the prosthesis as a natural and self-evident element of appearance.

Stripping Off the Body

Some pages after the scene in the bath tub, we see a diagrammatical structure (fig. 7) on the right side. In the centre of this page there is a

full-body illustration of the protagonist wearing a red cardigan and a blue skirt. A clear distinguishing line between her prosthesis and her leg is visible. Two physical handicaps are related to each other on this page: on the one hand, the obviously short leg, and on the other hand, a heart disease that had a strong effect on her athletic activities even before her leg amputation. According to the summary given on the page, this amputation caused only minimal changes in her everyday life and the interests she pursued. On the next right page the protagonist is presented naked and without the prosthesis (fig. 8). Only her parents, her “one and only boyfriend,” and “various doctors” have ever seen her like this. The following right page depicts her skeleton with muscles and organs (fig. 9).

This sequence of diagrammatical structures takes up the basic concept of a popular-medical manual or an anatomic pop-up image. On the first of the three following pages the stripping of the female body is already prepared: in the

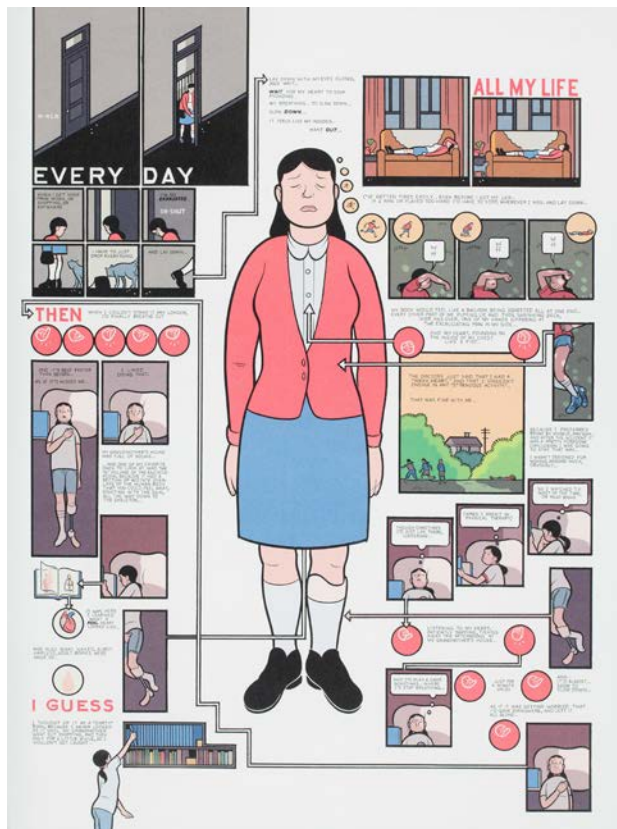


Figure 7

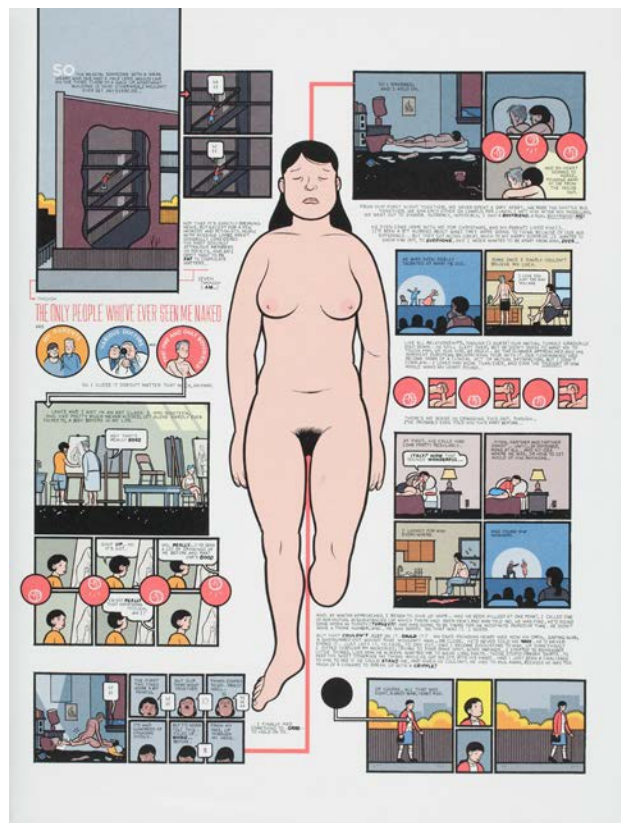


Figure 8

left bottom corner of the illustration the young girl opens an encyclopedia in a flashback with a chapter about the human body. The human body is illustrated on several transparent pages, one on top of the other, which by turning lay bare muscles and the skeleton. On the following pages, the protagonist herself is taking the part of object of medical study. However, unlike the examples in a medical textbook, this is not a standardized body. This becomes obvious on the second page, which shows the naked female figure. Although since the beginning of the 18th century, illustrations of disabled or deformed bodies were printed more and more frequently in medical textbooks, they were not intended to inform as much as entertain by showing bodies as curiosities of physical abnormality (Klotz, Lutz, Nürnberg, & Walther, 2001, 188–189). The protagonist is also exposed to this medical/pathological view, which she endures patiently with closed eyes, twisted eyebrows and the corners of her mouth turning downward. But the three consecutive illustrations invite another connection beside the pathological one: the

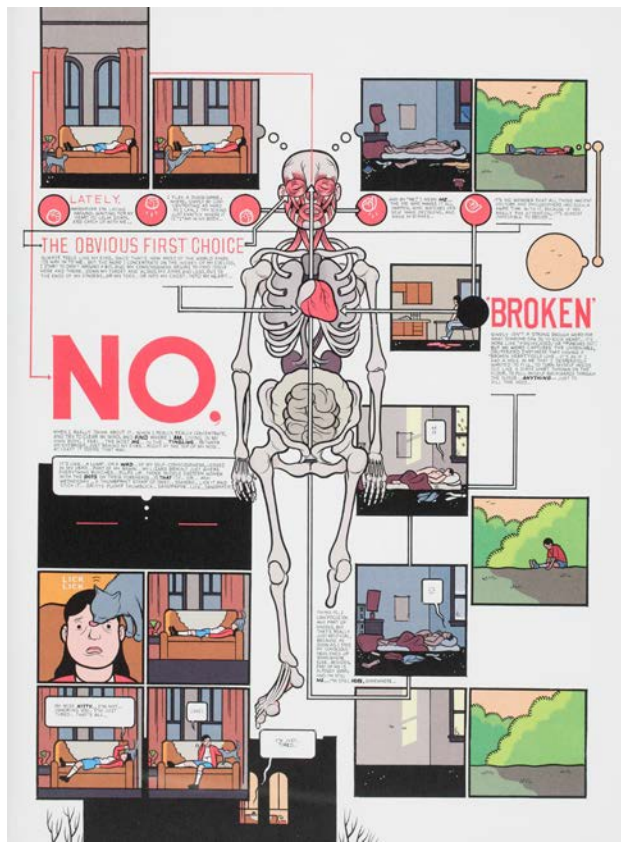


Figure 9

connection between body and soul. Illustrating the protagonist's body and her beating, and for a moment almost arresting heart, a connection is established to her sexuality – when discovering her body as a young girl, in intimate exchange with her boyfriend, and in masturbating. In the illustration of the skeleton, the heartbeat is transformed into a black hole, a symbol for the emptiness of her heart that was caused by the abrupt and disgusting end of the relationship with her ex-boyfriend. The heart in this anatomical illustration represents the intense emotions of its owner: "It's as if I had a hole in me that I desperately wanted to fill." Ware uses the diagrammatic structure of his work in connection with anatomical illustrations to draw attention to a complex field of associations of disability and emotional pain. What begins as an anatomical study of a body ends in a highly emotional, as well as challenging confrontation with the protagonist's mental state.

Conclusion

In *ANL no. 18*, Ware confronts the reading observer with his/her own prejudices by virtue of various strategies. A highly complex diagrammatical structure – which does not focus on the protagonist's disability – serves as introduction to the story. Only later, in subsequent panels, her short leg is illustrated as a natural part of her body. Only in relation to other figures, her prosthesis and short leg are associated with stereotypes of "disability as problem." Likewise her body is exposed to the medical – or more precisely pathological – view of the reading observer as a subject of physical abnormality. Socio-cultural background plays an essential part in the perception of this work of art: it is the reading observer who decides to a high extent if the physical disability is the main reason for the protagonist's loneliness and isolation – or not. By developing an awareness of the possibilities of interpretation and of the own frame of mind in relation to the illustration of disability, socially constructed limitations become evident to the reading observer.

In its hybrid constellation of text and image, the comic medium offers outstanding possibilities for the analysis of individual socio-cultural background. The ambiguity of the image and of the not completely describable surplus value of images invites the reading observer to think about him/herself. Likewise, the text in panels can mainly offer the horizon of allusions, as seen in the example of the bath tub scene. These art theoretical implications are also connected with a body-dimension, as the recipient is usually subconsciously establishing relations between his/her own and other bodies and/or the social construction of an ideal body. Marc Quinn uses this prejudice of the observer concerning bodies for his marble sculptures. Quinn's sculptures demonstrate how the observer's own socio-cultural background plays a role in completing the "missing" body parts of sculptures mentally. For Matthew Barney, prosthesis and physical disability bear positive connotations when empha-

sizing the potential of transformation processes and the sculptural qualities of prostheses. In contrast to Chris Ware, these two artists place strong emphasis on the body and his physicality in their works of art. Ware's approach to confront the reading observer with his/her own prejudices is more subtle and subliminal.

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- Fig. 1. First double page in *Acme Novelty Library no. 18*, 2007. Montréal (Québec): Drawn and Quarterly n.p. © 2014 C. Ware
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- Fig. 3. Detail of the double page in fig. 2 (right page, n.p.). © 2014 C. Ware
- Fig. 4. Marc Quinn. *Stuart Penn*, 2000. Marble, 160h x 98w x 54d cms, courtesy: Marc Quinn studio
- Fig. 5. Marc Quinn. *Alison Lapper Pregnant*, 2005. Marble, 355h x 180.5w x 260d cms,

Trafalgar Square, London. Photo: Marc Quinn studio

Fig. 6. Left page in *ANL no. 18*. n.p. © 2014 C. Ware

Fig. 7. Right page in *ANL no. 18*. n.p. © 2014 C. Ware

Fig. 8. Next right page in *ANL no. 18*. n.p. © 2014 C. Ware

Fig. 9. Next right page in *ANL no. 18*. n.p. © 2014 C. Ware

Endnotes

¹ *ANL no. 18* is part of a series that was begun by Ware in 1993 and up to now consists of 20 numbers. In a slightly modified form the volume is part of the voluminous project *Building Stories* which was published by Ware in autumn 2012 at Pantheon.

² Also Margret Fink Berman (2010) is arriving at that conclusion in an article, in which she developed her cultural scientific and disability theoretical thoughts and conclusions on the basis of a comic strip series with the same protagonist. I pursue the same assumption but with a different approach. My art historical method is based on phenomenological issues that are evolved from a detailed analysis of the specific works of art. With this approach I am pursuing the goal to emphasize the particular potentials of experience that can only be gained in preoccupation with works of art.

³ The expression “reading observer” is used in order to describe more precisely the recipient and mechanisms of reception: when opening a comic book, the recipient is first an observer as he/she perceives the entire double page and then the single page in its visual structure. Only after that he/she turns successively to the single panels, an action that is interrupted and expanded by the simultaneous observation of a single or double page.

⁴ Emphasis in original. This also applies to all following citations from *ANL no. 18*.

⁵ In the middle of the 19th century, the Fourth Plinth was part of the rearrangement of Trafalgar Square and was intended as the pedestal body for a second equestrian statue. This statue was never installed, so the pedestal body stayed empty. Since 1999 the Fourth Plinth has served as the pedestal body for various installations which are chosen by a committee.

⁶ “We stare with and at faces to know each other and the world. Faces mark our distinctiveness and particularity, highlight our appearance and look, indicate emotion and character, and display our dignity and prestige.” Garland-Thomson, 2006, 175.

⁷ *The Cremaster Cycle* consists of five films by Barney (1994–2002). For a detailed discussion of the whole cycle and *Cremaster 3* I recommend Eva Wruck’s dissertation, Wruck, 2014.

⁸ For a detailed examination of motives and relations in *The Order* see Wruck, 2014, 93–97.

⁹ Matthew Barney. *Cremaster 3, Mahabyn*, 2002. 1 of 3 C-Prints. For a reproduced image see Spector, 2002, 309.

¹⁰ Matthew Barney. *Cremaster 3, The Third Degree*, 2002. 1 of 2 C-Prints. For a reproduced image see Spector, 2002, 308.

¹¹ “One was to portray her as a model, and for that character we cast a pair of clear legs, and for the other we developed a pair of feline legs for her, which gave that character a kind of a cheetah physicality. I was interested in how Amy as an athlete would be running on carbon fibre-glass legs that were designed to give her advantage of the three jointed hind leg of an animal, or the cat.” Matthew Barney as cited in Wruck, 2013a, 133.

¹² In many respects Barney deals in his films of the *Cremaster Cycle* with transformational processes and sculptural qualities in most different connections, see Wruck, 2013b, & Spector, 2002.



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Facing Dyslexia: The Education of Chuck Close

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Research Articles

Abstract: Throughout his lifetime, the American painter, Chuck Close faced many challenges, including dyslexia and prosopagnosia. This article discusses his education and some of the creative strategies he employed to overcome the obstacles he faced from elementary school through college and graduate school. It also considers the influence of several of his teachers and the ways his learning differences came to influence his artistic process.

Keywords: painter, learning disability, education

Facing Dyslexia

The life of Chuck Close is a story of human challenges and accomplishments in three parts. His childhood, adolescence, and student years in Everett, Seattle, and New Haven, presented both ordinary and unusual psychological, personal, health, and educational struggles. As he entered into the first phase of his professional career as a teacher and artist at the University of Massachusetts at Amherst, he established himself as an original force in American art, breaking away from the mainstream. In the late sixties he turned away from abstract expressionism, and as a photographer, printmaker, and painter, he developed his own brand of large scale hyper realistic portraiture which directly opposed dominant trends in American modern art at the time. Later in 1988, his life shifted again as he had to make major adjustments to the way he lived and worked after experiencing a paralyzing spinal artery collapse. He refers to this health incident which caused his quadriplegia as "The Event." His life is a story of challenge, creativity, persistence, and the adaptation of technology. All of these things allowed him to continue to create and paint the reconstructed visions of human faces that became the art he is known for.

This essay focuses on the first phase of the artist's life, particularly his struggle with dyslexia, prosopagnosia, and a myriad of other childhood health concerns. It examines his educational journey through high school and junior college and the second part of his undergraduate career at the University of Washington. It tracks his graduate school experience at Yale, where through combination of original thought and labor intensive application, he began to emerge as one of America's most innovative artists. It considers the influence of teachers and mentors who were catalysts in Close's work, contributing indirectly to changes that would affect art history.

Chuck Close's experience did not follow a straight trajectory. In addition to the common developmental challenges any child growing up in post-war America would have experienced, he was also confronted with complicated health and educational challenges that probably seemed impossible to overcome at the time that he was a child. As he grew into a young man who would energetically challenge the artistic status-quo, some of the difficulties he faced would serve as a means to help him find solutions and processes leading to innovative visual expressions of the human experience.

As a child Close knew he had a talent for showmanship and the creative side of life. His father, Leslie Durward Close, who was a practical and creative man, supported his son's interest in puppetry and magic (Finch, 2010a). Home was a safe place that nurtured invention and imagination.

In contrast to home which promoted Close's creative side, he experienced difficulty in school. He struggled to read and remember the materials he encountered in text books. He

also had difficulty remembering and identifying the faces of the people he lived with every day. These two challenges that he experienced (and still experiences) are known as dyslexia and prosopagnosia. Dyslexia, which involves several areas of the brain, manifests complexly in individuals. A clear definition of this learning difference, which touches the lives of many, follows. It was developed by a working group of the International Dyslexia Association.

Dyslexia is a specific learning disability that is neurobiological in origin. It is characterized by difficulties with accurate and/or fluent word recognition and by poor spelling and decoding abilities. These difficulties typically result from a deficit in the phonological component of language that is often unexpected in relation to other cognitive abilities and the provision of effective classroom instruction (Lyon, Shaywitz, & Shaywitz, 2003, p. 2).

In addition to dyslexia, Close also has prosopagnosia, also known as face agnosia, or face blindness. This disorder has been known since the mid twentieth century (Ellis & Florence, 1990). It affects about 2% of the general population (Yardley et al., 2008). It is a neurological difference that results in an inability or difficulty in recognizing faces, despite adequate vision and cognitive skills to identify other stimuli like objects, letters, or words. Close has stated that he had difficulty recognizing classmates after spending a school year with them (Farley, 2011). The impact of this condition would have complicated efforts to connect with others.

Close faced additional challenges. Along with having near sightedness and lazy eye (Farley, 2011), Close also describes a neuromuscular condition which prevented him from running and using his arms in certain ways. "Not only was I a screwed up student, but I could not excel in sports... so as a kid when we were playing tag and everybody would run, they would run off and leave me. I'd run 25 or 30 feet and my legs

would lock up and I would fall down" (Tully, 1987).

Close also experienced childhood illnesses that were layered over these neuropsychological and physiological differences. One of the more significant of these was nephritis, a kidney infection which forced him to spend the better part of his eleventh year convalescing in bed. His father died at about the same time. These were two serious difficulties for a boy in late childhood who was about to face the changes of adolescence (Storr et al., 1998).

While these difficulties likely caused a great deal of frustration, sadness, and complication for Close as a child, the supportive and caring environment his parents provided allowed him to grow in his own direction. Close's father was a creative man who worked as a plumber and a sheet metal worker. He provided young Charles with the tools and props that would make his son happy as he applied his growing understanding of the world in ways that are not ordinarily found in a school curriculum. Amazingly, Leslie found an "art teacher" to give his young son painting lessons. Charlie's father got to know a young woman who had been a student at the Art Students League in New York. She lived near a diner he frequented in what may have been a house of ill repute. Nonetheless, she provided Charlie with lessons in landscape painting and figure drawing, complete with nude models offering positive reinforcement for the ten year old (Friedman, 2005).

Difficulties in School

In school, however, Chuck Close's struggles were significant. When interviewed for the book, *Chronicles of Courage, Very Special Artists* by Jean Kennedy Smith and George Plimpton about artists with disabilities, Close explained his understanding of the extent of his academic difficulties. He described himself as a slow reader with severe comprehension difficulties, unable to remember or recognize information for

exams. He felt that people saw him as a "shirker, lazy and dumb" (Smith & Plimpton, 1993, p. 15).

In 1987 Close discussed his difficulties in school with Judd Tully as a part of the audio recordings that were made for the *Smithsonian Archives of American Art* project. During those interviews he bluntly states, "I am dyslexic; no one cared." He reported being able to mirror write from age four and that, like Robert Rauschenberg, he saw an advantage to living with such reversals when he became a photographer and print maker (Gobbo, 2010). "I have no trouble imagining what it looks like the other way, using photos when making portraits or using other reversal processes for printing" (Tully, 1987). In the same interview he states that he has been able to mirror write fluently throughout his life. He also described his problems with facial recognition as a "part of the disability" (Tully, 1987).

Since no one addressed - or probably even knew about - the disability in Oakwood Elementary School or Everett Junior High School in northwest Washington during the early 1950s, Close was forced to develop his own processes for study. He had a great deal of difficulty comprehending and remembering the information he was required to learn in order to get through school. Close describes an elaborate process he developed as follows:

"I used sensory deprivation. I would go into the bathroom where I would -- in the dark -- put a strong light on a plank that I had across the bathtub with a book stand to hold the book and in hot water -- in total silence in the dark -- I would go over, and over, and over whatever it was I was supposed to be memorizing all night long before an exam. Just the very last minute that I possibly could go over the stuff. I was a virtual prune I was so wrinkled from studying. But it was like I had to get rid of all the other distractions and

everything else that was going on in order to focus and concentrate and stare at these things. Then in order to remember it I would take a word and I would break it down into letters. Then I would make a sentence. If I had to remember the name of a biological species or something like that-- say the word was -- I don't know what it would be--now, of course, I can't think of anything. [Laughs.] But if it were "plankton" or something like that, then I would put "please leave" da, da, da, and I would have a sentence. Then I would have a visual image of that sentence or it would be pink, long, or something that would be visual. So then when I'd need to recall this I would get the mental image, the mental image would feed me the sentence, then I would extract from the sentence the appropriate letters and rebuild the word. This worked reasonably well, but it of course ate up a lot of time. So typically on my exams if there were 20 questions, I would have the first 15 questions correct and then of course the last five I didn't have time to do. Now if you are a learning disabled person you can choose to take exams in an untimed way. For instance, you can take SATs and things untimed for people who have this kind of a problem" (Tully, 1987).

Those who teach students with language processing difficulties know the importance of teaching students who have reading comprehension difficulties to chunk larger groups of information down into manageably sized units. Early in life Close independently discovered the important teaching principle of chunking. He also discovered and used the cognitive science principle of mnemonics, a memory technique that allows the learner to translate concepts into formats that will be easier to remember. It is a technique that is now commonly taught to students with learning disabilities (Finch, 2010). The adolescent who developed his own process for reading comprehension and memory, would

as an artist many years later come to emphasize process in painting (Close & Dunham, 2007).

Close also used his abilities as a visual thinker and learner to get himself out of the occasional academic jam. He states that, "Art really saved my life because art is how I proved that I wasn't a malingerer" (Tully, 1987). He goes on to describe a ten foot long map he made that illustrated his understanding of the Lewis and Clark Expedition, which was being covered in his high school history class. For his English class he would make poetry books that included illustrations for every poem being covered.

School Strategies Propel an Innovative Painting Style

Close has stated that he flourished as an artist not in spite of his neurological conditions, but because of them. He has discussed the role his neurological differences contributed to his creative process: "If you break things down into incremental units, be they faces or readings, then it's just one little piece of information at a time" (Farley, 2011).

He is best known as a painter of faces. After he turned away from the influences of abstract expressionism and pop he began using a process to create hyper-realistic two dimensional likenesses of people's faces. His first well known work using this process was the mural sized "Big Nude," based on a photograph using a grid system to reduce the analog photo to smaller units to be transferred to the canvas. A large self portrait cropped in black and white using a similar process was followed in 1970 to create "Keith" using a three color process that resulted in a 9x8 foot canvas of a neutrally expressive face. These developed into the painting style he continued to use in modified forms throughout his career. The process depended upon hundreds of hours of intensive, meticulous, intricate painting.

Knowing himself, his strengths and weaknesses, Close adhered to this reductionist ap-

proach that was dependent upon very small units. Basically, he was taking the details of a face, which most humans use to identify others, and reducing it so that a complicated visual event becomes a flat plane in thousands of increments. Essentially this process is similar to the way that he tackled his school reading assignments. He captured sections of reading with his literal attentional flashlight while using the sensation or non sensation of warm water to filter out distracting sensory input. He broke the whole thing down into elements and used mnemonics to load it into his memory for later use.

Of course this took a tremendous amount of time and required a great deal of effort but it worked. Time and effort are two elements of life Chuck Close has always understood. He has always emphasized getting down to work and sticking with the process while having a willingness to take on large projects. He explained at one point much later that his work was time consuming. One painting could take up to a year, and the way of thinking he used was an outgrowth of his learning disabilities. When something is too big to deal with it has to be broken down into bite sized pieces. His work resembled that of a writer using individual words or a builder using individual bricks as they create a product (Smith & Plimpton, 1993).

Teachers as Catalysts and Mentors

When considering children and adolescents, like Chuck Close, who have struggled with learning and social challenges due to neurological differences in the way Chuck Close did, it is worth examining individuals who encouraged them to grow their talents. These figures are important because they have spurred struggling young people to find their gifts even when they are being overlooked by others. In other words, mentors can inspire hope amidst failure for people like Chuck Close.

The teachers and mentors who influenced Close, contributed to the face of twentieth cen-

ture art in America. Early support came from Close's parents who understood and promoted his interest in illusion and desire for visual expression. His parents, particularly his mother, Mildred Wagner Close, who had a complicated relationship with her only son after his father's death, always nurtured his creative side.

Having struggled through high school, the young Close barely managed to graduate. He was unable to complete the courses that would usually be prescribed for a young person interested in college or university. Guidance counselors recommended that he train to be an auto body worker (Finch, 2010b). At the age of 18, Chuck was a big fan of *Mad Magazine* and wanted to buy a nice car, so he thought, "Why not become a commercial artist?" He thought that perhaps at one time he might draw a cover for *Time Magazine* (Tully, 1987). His high school grades were mediocre and he had no chance of being admitted to the University of Washington.

Everett Junior College

Close benefitted from two instances of good luck. First, Washington had a junior college system with an open admissions policy. Everett Junior College accepted him as they would accept any other state resident who had graduated from high school. Close told his biographer, "I am a product of open enrollment" (Finch, 2010b). He explains his admission to college as having happened despite his learning disabilities (Smith & Plimpton, 1993).

The second piece of luck came when he met Russell Day. Day was the enthusiastic and dedicated chair of the art department at Everett Junior College. Close credits Day, whose former students included the glass artist Dale Chihuly (Luplow, 2012), with saving him from what might have been a boring middle class life. Russell Day has been recognized for his dedication to the teaching of art. He was reported to be a little eccentric at times, for example wearing a toupee like a hat when he felt like it (Roush, 2012). Day has spoken about his love of teach-

ing, recognizing what students bring to his classes, and staying aware of their potential (Lepper, 2008).

Meeting the right teachers was an important component in Close's development as an artist, but as in most situations that lead to success, effort and understanding played a role as well. As a young student Close became aware of what was necessary for an individual with learning disabilities to survive in the academic world. He said that he, "...realized I could find my own way to skin a cat—by doing work for extra credit, different kinds of projects, figuring out in which classes I could be successful" (Smith & Plimpton, 1993, p.16). His quest for creative solutions to his academic problems brought him to the classrooms and studios of several creative teachers who had a powerful influence on his development as an emerging artist.

At Everett Junior College Close met Don Tomkins and Larry Bakke who became important influences. Tomkins who Close refers to as his mentor while at junior college, was also one of Day's students. Tomkins designed jewelry and was known for pushing the limits of the medium to include elements like glass. When he returned to the college to teach, Close took metal courses from him. Larry Bakke taught Close life drawing and painting, and reviewed his final portfolio. Close graduated from Everett Junior College with an associate's degree in 1960.

University of Washington

The art student's next stop was the University of Washington (UW). Although situated on the other side of the continent from New York, which many perceived to be the center of the art world at the time, the University's faculty included influential artists who helped to shape Close's rapidly growing understanding of art, and the technical skills he would come to rely on as an artist. Two painters, Mark Tobey and Morris Graves who had become influential in northwestern art, were members of UW's art

department. Their classes would have a great effect on Close as a developing artist.

Tobey and Graves turned to the East rather than New York's east coast for inspiration, and were strongly influenced by the Asian experience and philosophy (Finch 2010a). Tobey, an abstract expressionist who won the Venice Biennale award in 1958 was influenced by Zen Buddhism and Bahia World Faith. He searched for the spiritual in art and was invited by Josef Albers to work as a guest critic at Yale's graduate art program. Tobey seemingly had a strong influence on Close's decision to later become associated with the New Haven program (*One Country*, 1998). Morris Graves was the younger of the two faculty members and he too was strongly influenced by the East. He had been to Japan as a young man, and in the Zen tradition he is said to have tried to capture the sound of surf and birdsong in his painting (Ament, 2003).

Larry Bakke's teacher, Alden Mason also served on the faculty at the University of Washington. Mason was originally from Everett, and Close respected and relied on him during his two years at the university. Mason describes Close as at first being a nervous student who painted "big gesture abstract expressionist paintings." It appeared that Close was trying to paint like Mason, but would come to Mason for affirmation of his work. Mason saw a different side of Close who usually appeared to be very self confident in front of his peers in classes and social situations (Harrington, 1984; Finch 2010a). Mason and Close remained lifelong friends.

Close was not afraid to move away from the painting styles of his teachers. In the spring of 1961, Close took a step away from abstract expressionism with his work, a large 10 x 7 foot American flag that he painted and altered, called "Betsy Ross Revisited." In the following fall he submitted it to the juried Northwestern Art Regional Show at the Seattle Art Museum. The influence of Jasper Johns and the recently

emerging pop art trend likely influenced Close's use of the flag to create the political statement that caused a stir in Seattle. He was beginning to make a name for himself.

During the summer between his junior and senior year at UW, Close received a fellowship to attend Yale's Summer Program of Art and Music in Norfolk, Connecticut. His admission to this prestigious program marked the first time that he was seriously recognized for his work. It exposed him to teachers with international reputations. Visiting critics included painters Phillip Guston, Elmer Bischoff, and the photographer Walker Evans, best known for his depression era photographs (Friedman, 2005; Storr et al., 1998). Close also had the opportunity to engage with the art and varied opinions of his fellow students: Vija Celmins, Bill Hochhausen, Brice Marden, and David Novoros (Finch, 2010a; Bui, 2008). Being in Connecticut brought him within striking distance of New York City where he could visit the museums and galleries he had been hearing about for the past three years. Close returned to Seattle and in 1962 finished his art studies at the university, graduating with the highest honors.

Yale MFA Program

After attending Yale's summer School of Music and Art and graduating with honors from the University of Washington, Chuck Close was accepted into Yale's MFA program in Art and Architecture. There, he was "immersed in the ethos of 1960's modernism" (Freidman, 2005, p. 28). He developed his technique as an artist while building a theoretical and practical understanding of painting, printmaking, photography, and art history. A shift in the school's teaching philosophy as it moved from the influence of Josef Albers disciplined Bauhaus teaching methodology to the freer approach that developed under recently appointed director and abstract expressionist, Jack Tworikov, undoubtedly benefited Close. Tworikov's approach involved exposing students to a wide variety of possibilities that could be in conflict with one another, and

allow students to be influenced as they engaged in their processes. "Rather than teach students to be artists – an impossibility- or indoctrinate them in a particular aesthetic, Yale's approach was to expose students to as wide a range of ideas and potential choices that could be bought under one roof" (Storr et al, 1998, p. 29).

This creative crucible was also influenced by Ad Reinhardt who was with Albers at Yale ten years before Close arrived. Reinhardt was the philosophical spokesperson for "The Irascibles," who were the most well known group of New York twentieth century artists. Reinhardt was a painter who wrote and commented on the philosophy that underpinned the abstract expressionism the group recognized. He was perhaps best known for his painting "Black on Black" the ultimate abstract work. Close was influenced by the ideas of Reinhardt, and like many students he was determined to do something that had not been done before. Reinhardt's words supported that approach and Close talked about that influence:

"... The artist who actually influenced the way I think most was Ad Reinhardt. In his writings he would say, 'You can't do this, you can't do that, no more this, no more that.' The whole notion of constructing limitations that guarantee you can't do what you did before will force you to do something else. And that's how you change, move forward; not necessarily progress, but how you can program change into your work" (Bui, 2008).

A more direct influence came from studying with Al Held, who joined the faculty in 1962, and taught at Yale until 1980. Held also painted abstract expressionist canvasses on a large scale. Close had a difficult time with Held's approach to teaching that tended to push works in progress toward a specific resolution. Still the student painter related to Held's working class background, and respected the older artist's advice on dedication to art and the importance of hard work (Finch, 2001).

In addition to the opportunity to study with painters like Held and get critical feedback from artists like Phillip Guston, Close was also able to work alongside and interact with fellow students who went on to successful careers. Examples include: steel sculptor Richard Serra and his then assistant, composer Phillip Glass, film maker and painter Nancy Graves, and still life painter Janet Fish, all of whom later became subjects of Close's paintings. A look at Rackstraw Down's paintings which depict photorealistic cityscapes on a large scale shows the influence of peers on the evolution of Close's work. Being in such a hot house environment of creativity had to accelerate the incubation of ideas and catalyze the young artist's process.

Summary and Conclusion

Looking at a time line of Chuck Close's life, one might conclude that attending Yale's prestigious graduate program to study visual arts would appear to be a natural next step. But given the struggles he faced in the earlier stages of his education, his completion of a graduate degree is a remarkable feat. In addition to and as a product of his determination, he developed and evolved study strategies that had to be continually sharpened in order for him to cope with the demands of a rigorous graduate school course load. He used his resourceful approaches of finding, "his own way to skin a cat," to complete his requirements in art history. For example, in Egbert Havencamp-Bergemann's class on the history of print making, Close replicated processes that were used more than 300 years earlier to gain a deeper understanding of processes used by 17th century Dutch printmaker Hercules Seghers. He used his experience to understand and explain methods used in that era. As a result of his studies with Havencamp-Begemann, Close began to understand both the chemical and collaborative nature of the print making process (Sultan, 2005).

In another art history class, his non verbal term paper prepared for Professor Jules Prown

was so impressive that the instructor later contributed it to the archives of Yale's Sterling Library. The response to an assignment on the topic of early American architecture and furniture compared a Hepplewhite chest to a Federal period villa by, "combining images reproduced from photographs with diagrams presented on acetate overlays" (Freidman, 2005 p. 320). This extension of his ability to break a problem down into its smaller parts that later could be reconstructed into a new view that revealed solutions, predicted his later direction in visual art.

Not surprisingly, there were less successful endeavors and setbacks that may have been influenced by the artist's learning differences. For example, Close worked as an assistant to printmaker Gabor Peterdi. While the older artist liked Close, the student was seen as being too disorganized for the master printmaker's work style.

Even though he faced obstacles Close gained an understanding of the history and process of print making. He did this in part by being able to see "and hold" the works of the masters like Rembrandt and Durer. "We were allowed to see and touch remarkable prints by Rembrandt and Durer, among others. I could study state proofs of Rembrandt's 'Descent from the Cross,' and clearly see the choices and decisions that Rembrandt made. I could hold them a few inches from my nose. I could see the process evolve through progressive states. I really understood print making for the first time" (Sultan, 2005). The art student is said to have left the experience seeing printmaking as something that would hinder rather than help him as a painter (Wye, 1998).

As is the case with many students who leave school with skills they feel are not the most useful at the time they acquire them, it is likely that the experience with printmaking under Peterdi and Havencamp-Begemann served him well some years later in his career when he became involved in print collaborations. Close's learn-

ing experience with prints and printmaking also illustrates the power of active involvement and "hands-on experience" for students with learning differences.

Chuck Close completed a double major in painting and printmaking in 1964. He then travelled to Europe on a Fulbright Grant, and taught briefly at the University of Massachusetts at Amherst. Close followed Al Held's advice and walked away from the security of a university teaching job to dedicate himself to his art. When he was a student in New Haven, Held told him to go to New York prepared to support himself as a painter through hard work. After his diverse college experience and the rigorous, dynamic work of graduate school, that is exactly what he did. From there, Close's national and international reputation grew to what it has become today.

Chuck Close's life is an example of dedication to developing processes to solve artistic problems. He believes ideas come out of this commitment to process and work. In part of a television appearance recorded by CBS's *This Morning* news show, Close offers advice to his "14-year-old self" (Close, 2012). This advice is perhaps among the best for anyone who has struggled academically. He states, "If you are overwhelmed by the size of a problem, break it down into mini bite-sized pieces." The micro-uniting and chunking processes he used while sitting in the bathtub, struggling with high school reading comprehension, served as the foundation for the process that would make him a recognized artist. Several years later he would take photographs enlarge them, then place a grid over the enlargement and paint them, one block at a time. The resulting hyper-realistic products literally changed the face of art history.

It would be a stretch to state that Close became a successful artist because of his experience with dyslexia and prosopagnosia, but they both are critical elements of his personality. Opportunities and the people around him also played

important roles in his growth, but his learning differences shaped his cognitive style and his approach to problem solving. They influenced the art he became known for and they are undoubtedly part of his creative process.

Appendix

Three of the following four url links lead to examples of Chuck Close's painting that appear on his official web site. The first two links lead to early works, *Big Self-Portrait 1968 (1.)*, and *Phil 1969(2.)*. Both are the result of taking a black and white photograph of a neutrally expressive face, and placing a grid over it. Close then paints each individual square of the grid to achieve a hyper-realistic portrait of the individual. These two paintings are approximately 9 feet x 7 feet in size. The third link connects to *Self-Portrait 1997(3.)*. This represents his later color work which extrapolates the earlier process. The final result is not concerned with realism and the artist fills squares with x's, o's, triangles, or other shapes to form the portrait. This painting is about 8 1/2 x 7 1/2 feet in size. A fourth url (4.) links to a photograph of the artist working in his studio.

1. Big Self-Portrait 1968 <http://chuckclose.com/work007.html>
2. Phil 1969 <http://chuckclose.com/work017.html>
3. Self-Portrait 1997 <http://chuckclose.com/work171.html>
4. Chuck close in his studio working on John 1992 <http://chuckclose.com/work155.html>

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Summer of 2012: Paralympic Legacy and the Welfare Benefit Scandal

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Research Articles

Abstract: Through the summer of 2012, two sets of images dominated the British press: welfare benefits scrounger and Paralympic superhuman. Through one claimant's traversal of the benefits system and against the heady backdrop of the Games, this narrative inquiry examines the profound and tangible consequences of these images, whilst offering hope for an abiding legacy that holds consequences for public perception of disability and the lives of disabled people.

Keywords: 2012 Olympic Games, perception of disability, disability benefits

Introduction

In this paper, I contrast the images of welfare benefits scrounger and Paralympic superhuman and describe their recurring themes, discussing the meaning each brings to the other and examining their shaping of perceptions of disability. I trace their impact through my personal traversal of the benefits system against a heady backdrop of the Games. Finally, I explore the deeper ramifications these images hold for us all.

Warm Up

In the summer of 2012, the British press was preoccupied with two contrasting sets of images of disabled people. The first consisted of widespread images of disability benefits claimants, positioned within a context of comprehensive benefits reform and a massive 30% cut from the national disability benefits budget (Edwards, 2012).

Two interwoven strands rapidly emerged: fraudster and scrounger. The first portrays non-disabled people defrauding the state via non-

existent impairment. They appear in family snapshots and surveillance video carrying out activities likely precluded by the alleged impairment: playing golf, digging gardens, and riding on a rollercoaster.

Scrounger reporting, in contrast, focuses on "workshy" disabled people who "languish" on benefits in preference to work, shifting the gaze from non-disabled fraudster to disabled parasite. Specific offences are replaced by generalized reporting, while amorphous photographs modeled by actors – stock images of normative bodies lain on sofas, television remotes in hand – portray scrounging as another version of fraud. Different types of benefit are conflated: whilst Employment and Support Allowance (ESA) is for those deemed "unfit" for work, all disabled people, employed or not, may claim Disability Living Allowance (DLA) as a contribution towards impairment and disability costs. In this new rhetoric, however, all claimants are cast as scrounger.

Negative coverage prompts hardening of public attitudes with an unprecedented two-thirds of the population believing benefits are so generous that they discourage job-seeking (Goulden, 2012). Public estimates of fraud range from 50% to 70% (Briant, Watson & Philo, 2011), as much as 230 times the Department for Work and Pension's figure of 0.3% (DWP, 2011).

Reporting is a narrative of criminality and moral bankruptcy. With government support (Newton Dunn, 2012), The Sun launches a "crusade" to "Beat the Cheat," providing a telephone line for readers to report on neighbors (Talsania, 2012). In the five-years to 2010/11, Daily Mail coverage of "cheats" increases five-

fold (Briant, Watson and Philo, 2011). Across the press, articles portraying disabled people as an economic “burden” multiply, and pejorative language (skiver, cheat, feckless) rises (Briant, Watson & Philo, 2011). The overriding message is uncritical support for welfare reform, in an account that portrays fraud as rampant and unites taxpayers against a national threat.

The character of non-disabled fraudster and disabled scrounger are equally under suspicion, but neighborly surveillance is not experienced equally. The fraudster has no identifiable impairment, so suspicion falls on those who do: was the wheelchair-user seen walking? Did the person with the white stick cross the road unaided? Was the ill neighbor seen out shopping (Begg, 2012)? A single case of fraud is implied to incriminate all disabled people; those whose impairments are visible are in the spotlight.

Disabled people feel the press message as a threat (Disability Rights UK, 2012). Added to anxiety about benefits reform, is surveillance, misinterpretation, disenfranchisement and hostility (de Wolfe, 2012) and a style of reporting that defames a community. At its extreme, an interview with the Minister for the DWP suggests disabled people are responsible for the entire recession (Newton Dunn, 2010).

In four years of financial crisis, I have watched figures for disability hate crime climb. By summer 2012, they have doubled and over half of disabled people have experienced hostility, aggression or violence from a stranger (ComRes, 2011). The scrounger rhetoric is a key player (Briant, Watson and Philo, 2011). Hate crime researcher, Katharine Quarmby, writes: “If you have a group that is blamed for economic downturn, terrible things can happen to them” (Riley-Smith, 2012).

Some seek to quell hostility through a counter image: disabled person as victim. In on-line newspaper comments pages, they reprise a contemporary version of traditional charity imagery, portraying disabled people as defense-

less and pitiable. Whilst it might lift immediate public opprobrium, to cast disabled people as vulnerable when hate crime is rising, plays a dangerous game.

The second image set emerges in the run up to London 2012 and could scarcely contrast more. The largest Paralympics ever, the most accessible and best attended in its 64 years (Topping, 2012), is promoted and reported on an unprecedented scale - over 500 broadcast hours and the most widely reported print news (Journalist, 2012). It contrasts starkly with reporting on benefits - a celebratory reporting of disability of exceptional magnitude.

As official broadcaster, and in keeping with government Paralympic legacy, Channel Four’s mission is to “[t]ransform the perception of disabled people in society” (ODI, 2011, p. 4). Matching the Paralympic motto, “empowerment, inspiration, achievement”, in a shift from its rehabilitative roots to world-class athleticism, the International Paralympic Committee aims to use sport to contribute to “a better world for all people with a disability” (IPC, 2003, p.1).

Media coverage launches through an advertising campaign. “Meet the superhumans” becomes a Paralympic mantra, echoed across all media and emblazoned across a larger-than-life glossy photograph of athletes, sleek and streamlined: swimmer, cyclist, runner, and wheelchair rugby player. Looking the viewer in the eye, they challenge them to dare to look back, dare to pity.

Once the Games are underway, a torrent of images appears of disabled people’s endurance and athleticism, impairment on view as never before, in a matter-of-factness of visibility. Hesitant early reporting becomes increasingly assured, in an awed weave of sporting triumph and individual “overcoming”. As medal counts rise, disabled athletes are fêted as heroes.

Topping the bill are back stories of shark bite, railway tracks, terrorism and war (Lusher,

2012; Lydall, 2012). The “hierarchy of impairment” is reenacted. Foremost are amputees with high technology prostheses. For spectators, the transformative powers of technology mark the apotheosis of superhuman.

Non-disabled audiences are initially absorbed by the athletes’ impairments, but notice their focus shift to sheer athleticism (BBC News, 2012). The press comments on Ellie Simmonds, and other athletes that “She ceased to be a disabled person. She was simply a champion swimmer” (Phillips, 2012, para.3). In a saturation of images, Games organizers and press predict these are images to change attitudes forever (Moreton, 2012).

At the closing ceremony, the Games are heralded as having “lifted the cloud of limitation” (Coe, 2012 in Collins 2012, para.1). The press ponders how extraordinary it is what, with determination, disabled people can do (Phillips 2012). The Paralympics spotlights a group who are at last “acceptable” to broader society. For most disabled people, it is an image to cleave to.

Lighting the Cauldron

The two image sets – inspirational Paralympian and immoral claimant – could hardly be more different, yet they have much in common. Replicating an ancient binary, they are a tale of extremes, of overcoming and inspiring versus flawed, burdensome and tragic.

Except for their intensity, their core messages would be merely a modernization of historic themes. However, unprecedented density and compressed timescales take them to new influence. In isolation, Paralympic coverage is an extraordinarily affirmative departure from traditional representations, yet its image borders are permeable. For most Paralympians are also claimants, whose DLA defrays costs of impairment and discrimination (while some also receive out-of-work ESA). That benefits are crucial to their athletic aspirations (Toynbee 2012), is almost entirely absent from the discourse of

either image. Where Paralympians are virtuous through implied self-sufficiency, other disabled people are absorbed into the scrounger rhetoric.

Despite polarization, both images tell a similar story: of individuals with impairments separate from social context. Whether by Paralympic success or claimant immorality, the individual is portrayed as soaring or plummeting through innate will.

In ignoring social influences – from discrimination and poverty to elite training and sustained investment – the press glorifies those who overcome disabling barriers (Hevey, 1992, 87), and admonishes the rest. The claimants’ reflected shame raises the athletes’ pedestal higher, each image reinforcing the other.

Disabled people visiting Olympic Park refer to the “Paralympic bubble” (Gentleman, 2012, title), with access and inclusion as we have never known before. Press reporting places the athletes in that same bubble, reassuring non-disabled audiences that “see... disability isn’t so bad... Those athletes seem to be getting on just fine” (Shakespeare, 2012, para.3). Coverage supports an illusion that any disabled person who excels ceases to be a disabled person at all. To be disabled, as those eligible for disability benefits must be, is to preclude excellence, whilst, for athletes, it is as though impairment and disability have ceased to be.

Since the meaning of images is influenced by the context in which they are viewed (Sturken & Cartwright, 2001, p.46), it shifts for different audiences. What it is to be disabled is not fixed, and Paralympic and benefits coverage changes according to audience concerns. Hence, the scrounger rhetoric meets approval from a population fearing that fraud endangers national interests, but threatens those at risk of false accusation. For many, the Paralympics is a positive new viewing of disability, even as it undermines disabled people who cannot conform to its exacting standards.

Through Paralympian, fraudster and scrounger, or the counter depiction of victim, the images center on individuals as source and solution for barriers. With serious consequences for disabled people's real lives, it is a barrage of images that reflects and bolsters government policy on austerity cuts and benefits reform.

As benefits reform pushes forward, it becomes clear that changes incorporate the most serious flaws of the image sets. The classification system that assesses entitlement to support also situates disabled people outside social context. Impairment is taken to indicate employability, without reference to discrimination, support or job availability. Classification has always been core to the welfare state, but this shift isolates claimants fully from their social context.

The Paralympics system is administratively separate, whilst overlapping in philosophy, with both systems built upon a common image that matches Paralympic representation. Quantifiable biomechanical descriptors, such as strength, flexibility and balance, which are used to allocate athletes fairly to competition, are also used to determine claimants' eligibility for financial assistance (Tweedy & Burke, 2009, DWP 2012b).

For the Paralympians, the measures fit, broadly, the physicality of the athletes, whose impairments are generally quantifiable (amputations, visual impairment, restricted growth, etc.) and who are being measured for quantifiable activity (power, endurance, etc.). Claimants, however, with typically more complex, hard-to-quantify impairments (chronic, fluctuating and life-limiting conditions) (DWP, 2012a)), struggle to fit criteria, which also fail to accommodate the range of generalized employment tasks. In basing benefits classification on an erroneous image of disability, it becomes a system unfit for purpose.

For those assessed, it is vital to match the assessor's "picture in the mind" of disability. If the prevailing image does not represent us as

disabled people then we fall through the net. Classification influences athletes' medal chances, whilst for claimants, it determines chances in life. The claimant deemed "fit for work" is not only without support, but subjected by the press to the charge of scrounger.

The "bubble" gives a distorted, simplistic view of impairment. Paralympians and claimants are viewed as bodily and socially equivalent, differences in outcome reduced to individual strengths and choices. In vastly different circumstances, the Paralympian is applauded, whilst the claimant is excoriated.

The two sets of images peddle a two-dimensional representation. Since the human mind responds to "metaphorically grounded" meaning (Lakoff & Johnson, 1980), their over-simplification converts to a symbol of what it is to be disabled. Ceasing to focus on the individuals portrayed - "this" claimant or "this" athlete - they become a commentary on all disabled people. Lodging in the mind, they become "the heroic Paralympian...and the burdensome gimp" (Peers, 2009, p.654), in a shorthand of values and judgment.

For disabled people, public identities become limited to scrounger and fraud, victim or hero. Somewhere between, in the invisible gulf, is the space that most disabled people inhabit.

Since most of the population claims to have little contact with disabled people (ComRes, 2010), the invisible majority remains unseen. Non-disabled people's primary source of meaning is the cultural media (Barnes, Mercer & Shakespeare, 1999), which teaches culturally acceptable ways of making sense of surroundings (Holtzman, 2000). In the absence of compelling, sustained alternatives, an under-informed audience takes its lead from the dominant rhetoric. Paralympics and benefits imagery holds the power to create a collective imagining of what a disabled person might be.

In casting disabled people as “other,” the images set disabled people apart (Stanton, 1996). Repeated references to “we” the taxpayer, “they” the claimant, “they” the superhumans, “we” the ordinary mortals, drive a wedge between disabled people and the rest.

The power of images is well known from another more sinister era. Paralympic imagery carries a trace of Olympia, Riefenstahl’s 1936 Berlin Olympics film, with its commanding aesthetic of an idealized physical type (Viggiano 2011). Simultaneously, National Socialist Party images portrayed disabled people as economic burden, readying the citizenry for a program of mass-murder that decimated the population of disabled people (Crow, 2010). Contemporary benefits coverage is charged with this same discourse. For National Socialists, the body’s state mirrors that of the mind (Mosse, 1996). Just as with Paralympic and benefits images, the body comes to indicate an individual’s moral character.

Consistently presenting disabled people as other than we are, these images leave us caught in the invisible gulf, yet simultaneously exposed to their crossfire. Any group made symbolically more alien, less able to conform, is made vulnerable to hostility and hate. In a public interrogation of who is to blame for the cuts, this is the most dangerous of places to be.

Sitting in the Games, I want to enjoy them wholeheartedly, to revel in the visibility of my community, the absolute naturalness of seeing them there, at home in the public wearing of their bodies. Entering the aquatics center through functional spaces, I pass through doors which open to light and height and blue. A third up from the pool, with dizzying tiers climbing sharp behind me, I am placed for the perfect view, the water a sheet of glass - empty, enticing, waiting.

Let the Games Begin

The brown envelopes, every time, set my heart thudding, announcing I must make public all that is most private, to be raked over by bureaucrats with images in their minds of people like me. It is the brown envelopes that spill news that my impairment of years, and all discrimination with it, has disappeared. Suddenly, through a peculiar logic of classification, I am found well enough to prepare for paid work I will never do. It is the same brown envelopes that herald months of waiting, of solicitors, evidence and tribunals, for a crime that isn’t mine. I feel I have the wrong impairment, but it is the system that is broken.

In the newspapers, I am feckless, cheating, scrounging, and languishing. You would never know that benefits are the safety net that anyone who has ever worked for money has already paid towards. Entitlement is forgotten and an assumption of guilt built into the system. I read that we all know someone who cheats in a world I do not recognize. But when The Sun launches its “Beat the Cheat” hotline, provoking neighbor to report on neighbor, I make sure to close the blinds before I walk across the room.

I should perhaps turn my fury to the fraudsters, except that, when my own claim fails, the newspapers have primed the public to believe that I am one too. The fraudsters are not the only ones who tell tales. Statistics tell that 299 disabled people on ESA are reassessed for every case of fraud (DWP, 2011). I have a creeping sense that we are not just dispensable, but too costly, taking up space that belongs to others. We have been dubbed “useless eaters” before, in another more lethal era.

At the supermarket, I notice I am holding myself differently - alert, vigilant. I sit taller and smile wider at strangers because now it seems safer. I act almost Paralympian, even as I am not, even as it betrays others who cannot do the same, even as I return home to recover energy I could never afford to waste. I go out even less,

become aware of lying low in self-imposed, protective invisibility.

It is the news of people dying that steals my breath, people found “fit for work” and dying, wronged, people who short-circuit the process in the most final and desperate way. It is my ten-year old, filled with life and justice, who gets it right. “It’s like the witches,” she says, well enough to survive the assessment and you cannot truly be disabled; to prove you are, surely you must die in the process. It is true that I am now too ill to be ill.

Ministers tweak the system to assuage difficult questions, and send guidelines to job centre staff on how to deal with suicide threats (Domoikos, 2011), while the death toll rises. We have become canaries down the mines, revealing a system that has become too toxic. As the Paralympics draws closer, I feel I shall implode.

The Opening Ceremony broadcasts to a billion-figure audience, and I recline upon my sofa to draft a defense for my forthcoming tribunal. In the background, disabled artists perform a high wire act.

The Games begin and every political agenda collides, as if a collective holding of breath is all at once released in a perfect storm.

If there is a single symbol of the storm, it is Atos, the multinational company contracted by the government’s Department of Work and Pensions to apply this new process of assessment. In “doing the dirty work of the DWP”, Atos becomes both architect and symbol of welfare reform, labeled as collaborators in this war on disabled people. As a primary sponsor of the Games, their logo is brazen on lanyards around the neck of every athlete. “It makes sense,” says comedian Mark Steel, “in the way that if you had a gay Olympics, you’d get it sponsored by the Pope” (Steel, 2012, para.1). The Paralympic authorities defend their excellent relationship with their sponsors and the athletes, with a few

audacious exceptions, hold their contractual silence.

Athletes are fêted as heroes, celebrated for determination and resilience. The press chorus’ approval, whilst the tabloids reaffirm a conviction that the rest are cheats and scroungers, shouting the news with energy revitalized. The countering message of victim sends chills down my spine. Each and every image makes failure a part of the deal. The athletes’ own benefits assessments are officially postponed until after the Games and I wonder what awaits them, out of uniform and back to looking like the rest of us. Yet, still, surveying all the options, I yearn to be a Paralympian. If they are superhumans, then where does that leave the rest of us? I find I have prosthesis envy.

Protesters take to streets and keyboards with terrier determination. The newspapers wonder provocatively that they can be well enough to protest and yet ill enough to claim, never grasping they are fighting for their lives. On comments pages, on Facebook and in tweets, there is mounting turbulence, a people’s despair cloaked in fury that spits and spews onto the screen. It is a two-week “window” to create another image that can communicate, galvanize, and give courage.

Disabled People Against the Cuts takes its “Closing Atos Ceremony” to the DWP (DPAC, 2012), hundreds of people filling the pavements outside with chants and banners, solidarity and resolve, in images that “talk back” (Garland-Thomson, 2009, 193) to those who would do us harm. Watching webcam footage, I revel in the visibility of my community, in the public wearing of their bodies and their rage. I know my heroes.

Inside Olympic Park, spectator-activists cover up Atos logos and deface the occasional lanyard (Pring, 2012). I take my own small protest to the swimming, wearing a black armband of mourning telling that “Atos Kills.” Deep in-

side, I long to stretch out in the Olympic blue of water.

In a ratings bid, the government adopts the Paralympics; it is a popularity contest for us all. In shaking a hand, presenting a medal, with a well-placed volley at those who disappoint, they confirm in the minds of many that there are those who inspire and others who scrounge. But I rally at the Chancellor's appearance, presenting a medal to the accompaniment of boos, a crowded stadium united in an aural Mexican wave (Channel 4, 2012). "Why did 80,000 people boo George Osborne? Because they couldn't fit any more in the stadium." That night, it is my sweetest sleep in months.

On the street, there is a sea of change. My electric trike draws admiration as never before. Strangers ask what sport I do, but faces fall as I am found wanting, though there's no more likelihood of my being a Hannah Cockcroft or a Richard Whitehead than there is of these ill-equipped strangers becoming Jessica Ennis or Mo Farah. A man wants to know why my chair is battery-powered when there are "much worse" who push themselves; am I lazy or what?

Back home, in the bosom of my family, watching the Games on television, we play impairment lotto. Any athlete spotted overplaying the inspirational card, we strike instantly and for life from all benefits.

The protests continue nationwide with phone jamming and banners unfurled. A coffin filled with messages is delivered to Atos; each note describes a disabled person's experience at the hands of Atos assessors, in a memorial to those who have died (The Void, 2012). And, at last, after more than two years of lobbying, we see the first critical shift in the press.

And perhaps this is the favor the Paralympics – even Atos – have done. Perhaps this is where perceptions can be "transformed," for they have given us a hook to lever a different kind of attention from the press.

Deep in the pages of *The Guardian* and *Independent*, even occasionally a lone stalwart in the *Daily Mail*, there begins another reporting. A small voice next to the tabloid screech, but a voice that might be heard, might start to turn a tide. Never yet shouting from the front page, nonetheless a door has opened to a torrent: the whistleblower pressured to misclassify claimants as fit for work (Brown, 2012), the vast numbers of decisions overturned at tribunal (HC Deb 4 September 2012. c17WH), the Atos doctors and nurses reported for professional misconduct (Lakhani, 2012), the exposure of targets for removing people from disability benefits (Long, 2012), the 90,000 accessible vehicles forecast to be repossessed (Toynbee, 2012), the government's threatened sanctions for disabled people who cannot comply with work-related instructions (Malik, 2012), and the 43% deemed too well for disability benefits, but too ill for work, vanishing from the records (Clarke, 2012), the prolonged stress, needless deaths and suicides (Sommerlad 2012, Wachman & Wright 2012). An economist confirms disabled people are "the hardest hit" (Edwards, 2012). Truly we are collateral damage in this war of cuts.

On an online forum, I read of the ex-con, guilty of embezzlement, offering to represent claimants at tribunal for a one-off payment (Toolbox, 2011), but he's scarcely more than a speck in the layers of deception.

I stumble upon the name of Unum, the US insurance company, advising the DWP in the design of its benefits assessment system. I read of their consultative role through successive British governments (Private Eye, 2011), simultaneous with their labeling as an "outlaw company" in the United States, guilty of denying multiple thousands of disability insurance claims (Mundy, 2011, para.4). I read of their claims-denial quotas and instructions to falsify medical assessment records (Jolly, 2012a). I read of the role of Atos in devising the assessment system, of the Diploma in Disability Assessment Medicine they run for healthcare workers subsequently

deemed qualified to assess claimants (FOM, 2012). I learn first-hand of the way these assessors “disappear” claimants’ impairments in a carbon copy of the process that saw Unum prosecuted (Kohn, 2009). I read that Unum’s medical officer moved post to become chief medical officer at Atos (Private Eye, 2011), and of Cardiff University’s Centre for Psychosocial and Disability Research, run with funds from Unum and a head from the DWP (Jolly 2012a). I see how they have rewritten the bio-psychosocial model for the purposes of benefits reform, privileging psychological factors to besmirch sick and disabled people as trapped in unemployment by their own lack of motivation (Jolly 2012b), all the while intoning that “work will set you free” (Jolly 2012a, para.1).

I read more than is good for me and layers of globalized interests and corruption, of greed and human dispensability, conspire in a weight of obscenity which dizzies down to a picture of me, pen in hand, as I place careful words on paper in defense of my future. Meanwhile, the government announces it has hardly begun on its plans for benefits reform. I quake in my boots at what lies ahead. In *The Washington Post*, a photograph (Morenatti, 2012) shows a protester sobbing, distress etched upon his face. Back home, I shed my own dark tears.

As I hurtle towards my tribunal, I am reduced to exposing my scars for public viewing. In this brave new world of benefit reforms, the assessment sets out to demonstrate what we can do (Grayling, 2011). Surely, it is born of a Paralympic ethos. But when my impairment is made to vanish, my appeal relies upon my cataloguing and parading all that I cannot. With no facility for cataloguing the effects of discrimination, I can only present myself as “unfit.”

The cost, the trauma, the reason people are killing themselves, is beyond assessments, beyond money, beyond tribunals; the cost is in what they represent. For who says I cannot work? It is only true that I cannot in this nar-

rowed way of doing it. In a system where work is required to be consistent, predictable, regular and sustained, then I cannot work, which is not the same as saying I am unfit for work. It is that there is no room for my way of working, of contributing. In a system that holds work as the indicator of a person’s worth, then I am, by default, of no worth. How did value come to be measured in such restrictive terms? Do I only contribute when I earn? Why do I not earn when I contribute? It is a stripping of self.

I have no option but to fight for benefits, for myself and others. But this is short term survival, clinging to the ghosts of autonomy, nothing more; it challenges nothing, leaves everything that is wrong untouched. Over the course of decades, I have built a life despite, to spite, all illness and discrimination. Finer than gossamer, it allows me to be me. Now, that meticulously crafted, oh-so-fragile security is trampled and my finite health is to be spent defending the threads that remain.

And in that moment before I hit rock bottom, before there can be no turning back, I realize how I am caught. To survive, I must deny all that I am, all that I have done, all that I might be. In order to get the financial support I need, I must fight to be written off in a system that is broken. This is the unspoken pact.

So now I know.

I almost lost myself the other day, but I am back, battered and exhausted, and ready to answer back.

Legacy

The Paralympics have “lifted the cloud of limitation,” says London 2012 Chair Lord Coe (Collins, 2012 para.1). I wonder next morning how other disabled people feel waking to grey skies.

In the immediate aftermath of the storm is a sense of hiatus. The athletes return to home-

coming parades, a brief hush descends upon the political machine, and activists give way to exhaustion for a while. It is time to take stock.

The first ever “Legacy Games” (DCMS, 2012, p. 8) has been a collision of images. A small glimmer for those who can match the abiding images of the Games, they threaten a heavy backlash for the rest. And as the Paralympic fanfare ebbs away, the benefits juggernaut roars on.

Legacy is a mercurial thing that sometimes must divert from its intended path. The Paralympics could have provided a platform for athletes and activists to communicate a more truthful representation of contemporary disabled people’s lives (Purdue & Howe, 2011). In the absence of that, I wonder if we can seize the opening to shape an alternative of our own.

In this moment, it is benefits reform that many of us must fight. By sheer necessity, by principle and solidarity, we support each other in a battle for survival, which depends, not on evidencing need, but on fulfilling “a picture in the mind.”

It is a picture nourished and reinforced by a “long campaign of misinformation,” uncorrected and indeed, fed, by government briefings that have fuelled hostility (Quarmby, 2012, para.7).

Individual benefits victories and grudging policy concessions can be no more than a short term legacy, or a reaction to crisis. Austerity, in its justification of welfare cuts, reporting bias, and of bending ourselves to fit, is a shield which diverts from deeper questioning of what lies beneath.

Immersed within the name-calling of superhuman/fraudster/scrounger/victim, lies an unease of greater magnitude, a resounding message of the social value placed upon disabled people. The images, in their polarization, are symbols not only of mythic disability, but of what we as a society value and abhor. As emblem, the

Paralympic superhuman has found its converse: disabled person as subhuman.

These are the values built into this benefits reform, in its assault upon disabled people’s futures and its relentless advance even as the deaths accumulate. It is these values that greet reform with widespread public support and an accompanying rise in hate. It is the same values behind other justifications: segregated education and threats to independent living, selective fetal screening for impairment and the rush to legal rights for assisted suicide.

It is a set of values that connects our every campaign, so to make effective change on one issue requires addressing them all. They are values rooted in history, yet experienced by contemporary disabled people as daily threats. Beneath the benefits rhetoric, is a challenge of “our right to inhabit this planet, our right to exist” (Bashall, 2012, 1h33’).

Simply to create alternative images – of “ordinary” disabled people between the extremes, who work and play, run homes, raise children, etc – is not enough. They are a partial view, of disabled people able to conform, but allowed to continue, untouched, the values that confine those in the invisible gulf.

Instead we need counter representations from an agenda of our own. We need to reverse the spotlight, “naming and shaming” those who do us harm, and telling a different story that shows what those who cannot conform can be in a system that would treasure diversity. It is not that people like us do not exist, but that we do not appear in the public gaze. To challenge the prevailing images through “visual activism” (Garland-Thomson, 2009, p. 193) is to produce images from out of the invisible gulf.

But we need to look deeper still. For behind the notion of disabled people as less, is a layer of values that reveres economic productivity and self-sufficiency. For those who do not, or cannot conform, their social value is dimin-

ished. What do these values mean for people kept from the workforce by discrimination? Or who cannot work because notions of work are so constrained? Or who are too ill to contribute in any endorsed way? We are left with no representation capable of reflecting dignity back to ourselves or demonstrating that we are of worth.

The image sets, and the structures built in their likeness, tell us little about disabled people and more about their non-disabled producers. They comment on the misinterpretation of what it is to be disabled and the function that disability serves within a society. They combine in a metaphor for hope and warning - the Paralympians symbolizing a “triumph of the will” over harsh times, the claimants providing a scapegoat and a rung on the ladder lower yet than our own.

In austerity, with unemployment climbing, the force of the images is magnified, even upon those previously immune. The values that impact on many disabled people now confront others too. In the face off between “do as you would be done by” and “every man for himself,” (Morris, 2012, 18’) lies the biggest battle of all, far beyond benefits reforms or cutbacks and on to the prevailing ideology that drives them (Williams, 2012), denigrating and disenfranchising all who do not conform. The message in these images defines disabled people’s life chances, but confines us all. And yet, for every one of us who does not conform, we shake it to its roots.

So here is an alternative for an abiding legacy. Beyond digging in, for those of us who have to and those who chose to align with us, is the possibility of showing another way. It questions both the imperative to conform and the shape of the mould. It is a possibility of imagining and demonstrating different ways of being, versions of ourselves that are as radically diverse as we are or need to be. It is a hope that in saying “we can do this better,” we might nudge towards a system that incorporates and includes, a re-reckoning of what makes any of us, disabled or not, human.

In the onslaught of images, campaigners and protesters, disabled people and allies, have shown what we can be in the most compelling picture of all. Away from the public gaze, in relentless defense of protecting a community, there have been skills and strategies amassed, abiding compassion, organization and resilience on a scale to move mountains. It is a different kind of productivity. There has been imagination and humor, alliances built, agendas shaped, the bearing of witness and feeding of courage. Fears have been allowed and defeat rejected. And, at the core, has been a refusal to comply, a pride in answering back, a quiet knowing that it is not we who are wrong. From out of the invisible gulf, our response to events is what defines us.

The summer of 2012 saw the perfect storm. And here is our legacy - to question the way things are and to show better ways of being in the world. It is another version of heroism, entirely visible if only people think to look.

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A Capabilities View of Accessibility in Policy and Practice in Jordan and Peru

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Abstract: We explore the recent evolution of accessibility-related policy in Jordan and Peru, and specifically consider issues around assistive technology access for people with severe vision impairments. We find differences in capacity development and institutions in the two countries over time and how it impacts the ways in which recent policy consultations have taken place, and propose a capabilities framework as a means to examine and contextualize these differences. Narratives of assistive technology use by people in both countries emphasize ways in which the capabilities approach is also a valuable tool in understanding aspirations and how social interactions evolve with access to assistive technology. We argue that the findings from Peru and Jordan, given the diversity of policy environments, infrastructure, and socio-economic attitudes towards people with disabilities, give us an important lens towards understanding the evolution of disability rights and policies in various low and middle-income countries around the world.

Keywords: assistive technology, cultural studies, visual impairment

The capabilities approach emerged as a framework for reexamining the issues of global welfare in human values beyond a monochromatic income view of development (Sen, 1980; Sen 1993). The approach came about at a time when discussions of development were dominated by a small set of macroeconomic indica-

tors which were measured to indicate the level of progress for nation-states. Capabilities thus shifted the attention away from, not just what the individual and collective in a society had functionally attained in monetary terms, but took a holistic view of the freedoms that were experienced in various societies, and how these in turn could be examined to create a broader measure of quality of life. While the central idea of understanding non-monetary measures of well-being has been a foundational principle of this lens, the approach has since undergone as many transformations and interpretations as the social conditions it examines (Nussbaum, 1995). The adaptability of the capabilities approach enables it to reflect the diversity of the human condition – to serve as a lens to examine a range of situations where existing inequities may result in some form of marginalization or capability deprivation. Applied to the experience of physical and sensory impairment, the capabilities approach provides a valuable framework for embracing the multiplicity of conditions that constitute the experience of individuals with disabilities. In representing a departure from utilitarianism, the capabilities approach encompasses both the immediately measurable achievements such as access to services, income, education among others, as well as the ability and freedom to conceive and achieve it (Sen, 1987). Cultural studies have adapted this in the form of a “capacity to aspire” (Appadurai,

2004) as a means of interrogating the ways in which culture impacts the ability and intent of a society to be more inclusive. Thus cultivating aspiration as “navigational capacity” is a means for empowering individuals to exercise agency over their own participation with society. We use this perspective to our study of Accessible or Assistive Technology (AT), since the instrumental purpose of AT is to enable means of access to abilities and aspiration, and our own past work shows that AT impacts the sense of social and economic aspiration among people with vision impairments (Pal, 2010).

Several key ideas of the capabilities approach are relevant to contemporary discourses on disability and society, particularly with regard to social and economic barriers to opportunity. Ideas such as individual differences in the ability to transform and use resources, the importance of a range of material and non-material factors contributing to sense of well-being in society, control over our environment, the distribution of opportunities in society, and the functional ability to act on substantive economic, political and cultural freedoms are all ideas that have been used to operationalize the capabilities approach. These ideas are important in understanding the social inclusion of people with disabilities, particularly in societies where policy around disability is actively evolving.

Both disability and poverty, which has been a much more common area of research on capabilities work, are defined and exacerbated by the existent level of accessibility in the respective contexts of their operation. Over time a number of important works have confronted issues around disability and agency in a range of theoretical and disciplinary traditions including gender studies (Nussbaum, 2007), policy (Mitra, 2006), learning sciences (Terzi, 2005; Reindal, 2009) and social exclusion (Burchardt, 2003). Work using the capabilities approach has made a prominent theoretical impact on the mainstream disability studies community (Baylies, 2002; Burchardt, 2004), and the last decade has

seen an important increase in work in this space, particularly looking at the developing world (Trani, Bakhshi et al., 2009; Groce, Kett et al., 2011; Graham, Moodley et al., 2013).

Fundamental principles of agency and opportunity have been elemental concepts in the building of disability studies from the early days of the formalization of the social models of disability (Finkelstein, 1980; Groce & Groce, 1985; Oliver, 1997), and in the negotiation of disability as identity (Linton, 1998) as well as its cultural representation by the mainstream (Shakespeare, 1994). Work on the social models of disability, which discuss the ways in which structural and cultural aspects – ranging from the lack of accessibility in public spaces to negative attitudes towards people with disabilities are what shape the experience of disablement rather than the physical condition, *per se*. This is an important shift away from the “medical model” of thinking about disability which defines disability in terms of an individual’s physical or sensory impairment, often as something to be cured, rather than as society’s inability to be accessible to all.

Our contribution here is to expand the capabilities approach into thinking about assistive technologies and aspiration. We do this starting at two points for examination of capabilities perspectives – the policy-making approaches on AT, and the experiences of AT access and use from individuals themselves.

First, we examine with a capabilities lens the planning process related to implementing disability policy. The discourse around progressive disability rights policies in Low- and Middle-income Countries (LMICs) is invariably tied in with broader questions of economic development. While these discourses can be observed at various points in the public sphere, there can be few more important loci of examination than the experiences of people with disabilities themselves.

Second, we consider a capabilities approach to the use of assistive technologies for people with vision impairments, in this piece specifically with Jordan and Peru, but by extension in the context of the developing world more broadly. We examine assistive technology as an artifact of capability enablement, what one may call an element of freedom itself. We discuss results from interviews of assistive technology users with vision impairments in Jordan and Peru, examining the extent to which the technology has been a factor in increasing their access to economic and social opportunities in the public sphere.

A Capabilities Lens to Disability Policy and Accessibility Planning

The opening of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) brought to fore the first major international policy document urging nation states to create a greater culture of accessibility, and to consider inclusion from a rights-based view of disability. The UNCRPD created history by being the most signed convention on the day of its opening. Many signatory nations are among the poorest nation-states in the world. The early years of implementation of the UNCRPD has led to an increase in scholarly research relating to disability rights and accessibility in the developing world (Hernandez, 2008; Kett, Lang et al., 2009; Szymanski, 2009; Ahmad & Ahmad, 2010; Aldersey & Turnbull, 2011; Meekosha & Soldatic, 2011), and more specifically on the need and scope of assistive technology in these regions (Eide, Oderud et al. 2009; Pearlman, Cooper et al., 2009; Simpson, 2009; Kelly, Lewthwaite et al. 2010; Borg, Lindström et al., 2011).

A capabilities approach is salient in thinking about disability policy because of the centrality of agency and opportunity in the global history of disability rights activism. The phrase “Nothing about us without us” has been a fundamental principle of the disability rights movement in

much of the western world, and has come to typify the representation and consultation of people with disabilities in decisions related to social and economic inclusion (Charlton, 1998). Though signing the UNCRPD represents an important first for many nation-states, enacting its principles meaningfully requires states to make sizeable investments. For citizens with disabilities in LMICs, the CRPD represents a hope of greater inclusion, but also a risk that their governments’ priorities in areas like poverty reduction and nation-building will trump immediate attention to investment into accessibility.

The ability of nation-states to culturally interpret international law has typically meant that the implementation of several such conventions is varied and dependent on appropriation of the nation-state in question, as has been seen in the cases of human rights (Hathaway 2001), women’s rights (Cook 1989; Venkatraman, 1994), and torture (Miller, 2002). In the discussion of capabilities, such a cultural argument is one of the important warnings that Martha Nussbaum puts forth in her contemplation of global gender issues (Nussbaum, 1995). From an international law perspective, the granularity in outlining specific rights and responsibilities is very important. Greater specificity has the benefit of highlighting the importance of each set of rights, but also offers the risk of the blatant non-fulfillment of those mentioned provisions. The CRPD is fairly detailed in noting particular needs including workplace accommodation, low-cost AT, public access, education, rather than a shorter document with a more general call to commitment. Yet, along this specificity is a language that allows nation states flexibility to move towards goals at their own pace.

There has been little work that brings together issues of policy alongside the voices of stakeholders with the primary experience of disability in the public sphere. The process of planning an “implementing” of the convention involves legislative work, as well as a significant process of setting up earmarks and priorities for

spending. It requires a recalibration of existing disability-related laws in language and in spirit. In several countries, the CRPD has been the default framework for disability given the lack of any existing disability-related legislation.

Lastly, it is important in the capabilities discussion to note the role of Disabled Peoples' Organizations (DPOs). Most countries around the world have at least some existing network of DPOs and many cases these have been the de-facto campaigners for rights, policy, and services. The role of DPOs is critical in understanding accessibility policy from a capabilities perspective since these are composed of people with disabilities and are often the channel for the voice and narratives of individuals and their experiences. As organized entities, DPOs have frequently been at the forefront of agitation around disability rights, and in many countries have been conduits if not the very providers themselves, of services for people with disabilities (Miles, 1996).

DPOs can also be instituted very differently based on what is the standard for the places where they exist – in Jordan, for instance, we found that DPOs, like NGOs in general, are highly beholden to the government, and are often overseen by representatives from the government. This paradigm is common for a number of countries with more centralized forms of governance. In contrast, Peru had a very independent DPO sector which had a history of openly voicing its dismay with policies and advocating for change.

Policymaking for implementation of the UNCRPD and its social model for disability therefore requires a basic accordance with the principles upon which the Convention is based. The Convention is unique in its explicit delineation of those principles, articulated in Article 3 and including provision (c) “Full and effective participation and inclusion in society.” The unequivocal nature of this guiding principle is further contextualized by the one that follows,

(d) “respect for difference and acceptance of persons with disabilities as part of human diversity and humanity.” In order for a disabled citizen to have full and effective participation and inclusion in society, the unique capabilities and characteristics of that individual must be recognized. This individual must have a voice in the creation of his environment. Indeed, as Valerie Karr notes in studying UNCRPD implementation from a quality of life perspective, self-determination was a powerful indicator of quality of life. Clearly embracing the capabilities approach in its guiding principles, the UNCRPD identifies certain bases upon which effective policy-making rely (Karr 2011).

Assistive Technology Within the CRPD Environment

In this paper, we apply our theoretical framework to the experience of vision impairment and the workplace, specifically concerning Assistive Technologies (AT) and socio-economic opportunities. We primarily focus on computing-based AT such as screen readers on PC or mobile platforms, accessibility and way-finding apps which are used for geographical navigation, magnification technologies as well as Braille displays, all of which allow a person access to computing and networking. For people with vision impairments, the importance of AT in economic and social participation has been fairly well documented in the last decade, especially as computing has become ubiquitous in the workplace (Mackelprang & Clute, 2009; Fok, Polgar et al., 2011).

The importance of AT and Accessibility in the CRPD is notable from its mention in instances -- Articles 4 (General Obligations), 9 (Accessibility), 20 (Personal Mobility), 21 (Access to Information), 26 (Rehabilitation) and 28 (Work and Employment) each cite the obligations of state parties to develop, provide, and sustain low-cost assistive technologies, workplace accommodation, and accessibility for their populations. Although there has been some work

on the scope of the Convention (Kanter, 2006) and on the education of children with disabilities in relation to the convention (Hernandez, 2008), there has been little research on contextualizing AT to the ground realities of employability and social participation in LMICs. There are a number of technical concerns about access to AT, in large part because these technologies are often designed with a western audience in mind, optimized for the operating environment (bandwidth, language, processor capacity) of computing environments in industrialized nations. Likewise AT tends to be unaffordable in LMICs, and employers are rarely willing to invest in them. Our goal here is to examine the techno-deterministic idea of AT representing capability – that technology can level the playing field. To do this, we first examine the recent disability policy making process from a capabilities perspective, and then consider the narratives of individuals talking about their recent workplace experiences.

Empirical Research

Jordan and Peru are economically on the higher end of the LMICs, but the two offer interesting contrasts vis-à-vis accessibility and the implementation of disability rights. The selection of the two countries was done based on stratification of countries first based on their income, size, status as CRPD signatories, and regional diversity. We finalized on Peru, Jordan, India, and the Philippines to cover a broad regional diversity in size and income, and from that narrowed in on Peru and Jordan in part because of the receptiveness of local partners to work with us, as research of this nature is very difficult without significant access to policy professionals, and to non-governmental organizations active in this space. At the time of starting the research, Jordan was representative politically and in size to a number of the other countries in the region (though that has changed due to developments since), and Peru likewise was an important middle-income Latin American country comparable on demographics, urban-

ization, and economic diversification to several other countries in the region.

We conducted a textual analysis of the available CRPD reporting documents and associated materials from Jordan and Peru. We overlay our policy discussion with in-depth interviews with 75 individuals with vision impairments – 25 in Jordan, and 50 in Peru. In the interviews (30-90 min), respondents discussed issues related to their public sphere experiences, particularly in reference to their AT use. Interviews in Peru were conducted in Spanish, in Jordan, in Arabic, and in person – by researchers from the respective countries who are part of the team of authors. The excerpts used here are verbatim translations.

Of the total 75 respondents, 65 were employed full or part-time. This is not representative of the general population of people with vision impairments, which tends to have a lower rate of employment, and higher incidence of poverty. As we find below in Table 1, our surveyed population has fairly high education, with the majority in both countries having some form of college education. Arguably, our sample being restricted to only those who use some form of AT reduces the number of poor individuals represented in the work. In a sense, this research represents the professional elite within the community of people with vision impairments.

All interviews were coded by team members, 121 codes were used in all, and the entire sample had a total of 1206 codes. All the interviews were read at least three times by various team members contributing to the coding process. The coding was done by the larger team of researchers, thus the data from each country was examined by other team members for triangulation. The themes we discuss in this paper are independence and capability deprivations – both social and structural.

Table 1: Sample description by highest degree of education

Country	Gender	Primary School	High School	Some College	Vocational Degree	Bachelors Degree	Masters Degree	Professional or Doctoral	Total
Jordan	Male	1	4	0	1	4	6	2	17
	Female	0	1	0	0	6	1	0	8
	Total	1	5	0	1	10	7	1	25
Peru	Male	0	0	5	7	5	0	9	26
	Female	0	0	2	11	0	2	9	24
	Total	0	0	7	18	5	2	18	50

Disability Policy, Post CRPD: Planning Analysis

In both Jordan and Peru, the recognition of a social- and rights-based model of disability begins with the involvement of DPOs and activists in the planning process related to the disability

immediate aftermath of the CRPD, there was a national law (#31) on the Rights of Persons with Disabilities. In January 2012, a consortium of DPOs and activists put together an independent report discussing the progress around specific articles in the convention in Jordan, which levels a number of critiques of the state of affairs.

Table 2: Principle themes used for analysis of interviews

1. Theme: Independence and Empowerment

Nested codes:

- a. Independence increased by AT use 99 instances
- b. AT increased socialization 81 instances
- c. Privacy through AT use 23 instances
- d. Aspirations raised through AT use 66 instances

2. Theme: Capability Deprivations (Structural):

Nested codes:

- a. Infrastructure problems 18 instances
- b. Public transportation problems 49 instances
- c. Problems in educational accessibility 52 instances
- d. Quota implementation & underemployment 36 instances

3. Theme: Capability Deprivations (Socio-economic)

Nested codes:

- a. Lack of societal awareness 78 instances
- b. Discrimination in society 66 instances
- c. Low possibilities of growth at work 21 instances
- d. Low physical accessibility at work 22 instances

policy. Jordan signed the convention on the day of its opening on March 3, 2007 and ratified it exactly a year later on March 31, 2008. Till 2013, Jordan had not submitted an official progress report to the UNCRPD Committee. In the

The national approach of Jordan towards disability issues is defined by a two-phase National Disability Action Strategy. A look at the bases for formulation of such strategy, however, raises concerns as to the potential efficacy of its content in producing outcomes reflecting the

principles of the capabilities approach. First, the strategy adopts a “medical welfare” definition of disability (Al-Azzeh, 2012). The centralized nature of Jordanian policy-making purports a top-down strategy for disability policy which is guided by the available store of consolidated information, rather than a strategy based on public discourse. Consequent limitations in the breadth and depth of information on the lived experience of disability in Jordanian society become a significant gap in the resulting policy. One important manifestation of this distance was in the lack of disaggregated census data collection that represents the geographical and gender distribution of disability (Al-Azzeh, 2012), without which effective planning and earmarking of funds for citizens with disabilities is extremely difficult.

Participation of DPOs is a key issue in Jordan, which were excluded from formal representation at the preparation of official CRPD discussions. This problem is further exacerbated by the confluence of overlapping governmental organizations and jurisdictions dealing with persons with disabilities (Al-Azzeh, 2012). The state-controlled High Council for Disabilities was not only responsible for CRPD compliance, but had become the *de facto* assistive technology provider for many persons with disabilities, not the original mandate it was set up for. The lack of connectedness with ground realities was reflected in this fact when the High Council decided to distribute laptops and screen readers directly to individuals as part of its AT investments, which were immediately sold by the beneficiaries in the market. In the words of one respondent, “No one asked them what they wanted. They were not consulted on which Screen Readers and which laptops they wanted to use.” The intimate relationship of NGOs with the state in Jordan (Schlumberger & Bank, 2001) meant that there was no effective counterbalance role played by civil society or DPOs in the process, as these were all beholden to the Ministry of Social Development which licenses them. The Jordanian case also underlines one

critical element with disability policy in similar LMICs which may not have existing systems in place – the High Council’s work frequently overlapped with that of several other agencies and there were frequent issues with Ministries of Social Development and Education on jurisdiction.

Interestingly, there has been a collaborative planning process in place for the consultation of activists through an informal campaign referred to as ‘Takafu’ in which various stakeholders met with state officials practically on a weekly basis. The campaign engineered changes to the constitution on voting laws for persons with disabilities through consultations with ministries even though there is still a welfare-based approach to the wording. The Takafu campaign underlines an unusual irony – while on one hand the informal, stakeholder-led meetings were able to campaign for better rights, the very nature of centralized decision-making meant that the informal group had the kind of influence that a regular bureaucratic process may have undermined.

And yet, this very nature of informality meant that the Takafu’s role in changing laws was not furthered into a long-term collaboration between persons with disabilities and the civil society and the government. Thus we find in Jordan a division between intents and outcomes. This division, as we discuss in the narratives of AT users themselves, is the legacy of a medical model, cultural issues related to perceiving disability in welfare terms, and the resulting lukewarm integration of people with disabilities and DPOs. This, alongside the fact that Jordan has not ratified the Optional Protocol, this further diminishes individuals’ control over their own rights and continued self-determination.

Peru ratified the convention and protocol in January 30, 2008, and started applying both documents on May 3, 2008. Unlike in Jordan, there had been a history of aggressive activism by DPOs, and a general law for people with

disabilities in 1999 followed by a 2003 “Plan for Equal Opportunities.” The plan linked disability to the relationship of people with their surroundings, as a move away from the medical approach traditionally applied in legislation, and was the first to specify the need for AT and for ICT training centers. In 2005, there was the promulgation of a law for the promotion of internet access and physical accessibility of public internet facilities for people with disabilities.

Thus in Peru we find important roots of a capabilities thinking towards disability well before the CRPD, and this is indeed reflected in recent reporting. Jordan’s basic rights on voting were still being sorted through at the time of publication. Peru on the other hand, had a Plan for Equal Opportunities (2009-2018) to follow through to the previous decade’s initiatives. Similarly, on the planning front, unlike the informal approach of the Takafu’s consultations, in Peru the Disability Commission (CONADIS) was explicitly codified into the process by inviting “associations of persons with disabilities and their relatives to take part in the election of the five representatives of persons with disabilities and their families who are to sit on the commission.”

CONADIS has held workshops in various cities throughout Peru starting in 2008, soliciting feedback from DPOs and individuals with disabilities for the elaboration of this plan. In its report to the CRPD, Peru noted progress on a number of subject areas, and made specific monetary earmarks such as towards Article 5 (nondiscrimination), Article 26 (Rehabilitation) and in particular Article 33 (Monitoring) which underlines a commitment to scrutiny. However, a number of other key areas including gender and disability, independent living, and political participation are not mentioned (Peru, 2010). An important trend of democratizing the discourse on disability policy in both countries was the existence of parallel reports and publications commenting on progress. Peru’s parallel reports submitted by civil society offer a defini-

tive glimpse of the latent problems with disability policymaking, noting that “there is no seriously structured and coordinated policy inside and outside the government that systematically includes activities for the promotion of employment” (CONFENADIP, 2010). Unlike Jordan, Peru has ratified the Optional Protocol so its civil society may file complaints directly with the UNCRPD Committee.

As we see in the two cases, there are important similarities and distinctions in the articulation of human capabilities and participative planning in addressing disability rights in the two countries. An important shortcoming referred to by respondents in both countries was the lack of effective information gathering on disability issues. Both countries had no disaggregated ability-based census; neither country had any formal examination of citizens’ experiences with disability. Our following discussion of individual narratives helps understand the policy mechanisms alongside the realities of how people with disabilities participate in the public sphere, and the extent to which this has changed in recent years. While our policy discussion includes issues widely applicable to disability, our interviews were only with people with vision impairments. Nonetheless, the narratives of individuals offer critical insight to contextualize the policy developments from a capabilities view.

Narratives: Independence

Our user narratives represent over 400 pages of transcripts. We summarize only two themes here that are specifically related to capabilities. A striking theme was the extent to which people discussed AT as being important to social and economic independence. The distinction between potential and actual disability can be operationalized through the restrictions an impairment places on the individual’s functioning (Mitra, 2006). This emerges strongly in the way that AT represented a reversal of various structural barriers. For our respondents, this extended

from being able to use screen readers to participate in policy consultations to basic day-to-day economic and social functioning. For respondents in both countries, the idea of long-term care or economic dependence was frequently a fundamental part of the growing up experience, largely due to structural restrictions and a widespread negative visibility of disability, which depicts disability in terms of charity (Frix, Pal et al., 2010).

A starting point in the respondents' note of participation in public policy specifically or the social sphere generally was their expansion of social networks once they had access to AT. The work on vision impairment and social networks has shown that individuals' networks can be fairly reduced to a limited inner circle of connections (Lind, Hickson et al., 2003) which exacerbates the problem of lacking social networks and support needed for employability (Cimarolli & Wang, 2006). Recent work has started looking at the role of the internet in social support and expansion of networks for people with vision impairments (Gilson & Xia, 2007; Smedema & McKenzie, 2010). From our discussions here, we find that in both Jordan and Peru access to AT expanded networks and social support, and in turn provided sounding boards for policy participation.

“Before we felt somehow excluded from this virtual world because we didn't have the accessibility we have now. Now we participate much more. I am even in contact with my friends from high school and university on Facebook, before I wouldn't have imagined how Facebook or Twitter works. Now I can even interact with people outside this country, in other countries, in the other side of the world, thanks to social networks” (P.22).

Mirely, Female, 37 yrs, Lima

For people with vision impairments, the loss of privacy is often cited as an important barrier to independent living (Keeffe, Lam et al., 1998).

We found in discussions that the problems with privacy in communication extended through a range of participative functions – from unfettered political discussion on forums related to policy to even the most basic forms of social participation in both countries.

“I don't need my mom to read my private stuff. I can chat with other friends, to read my Facebook or download music from YouTube, anything. (...) The difference now is that I can listen by myself, I can listen to a book by myself, I can listen to anything I like by myself, I can look for information by myself. Before I had to ask my mom or a friend, sometimes I asked them to chat for me, they even knew my password” (P.6).

Silvia, Female, 35 yrs, Lima

The ability to build and sustain economic activity on individual terms was a really important part of access to AT. Peru has had a comparatively more strident disability rights movement in recent years. This has resulted in slightly better access to AT. Schools and institutions have for instance been providing access to various kinds of AT for relatively longer, even though there is a significant population that slips through the cracks on AT access. In Jordan on the other hand, systematic access to AT through institutions is relatively new. In our sample we find that Peruvians at an average had been using AT longer than Jordanians, for instance, even for an individual who had an electronics business in Amman had never come across AT until recently. In this respect, Jordan presented a problem that may occur across other LMICs as well – of individuals never having used computing-based AT before adulthood.

“So for example, I have a private business buying and selling computers. I would get some adverts and deals over the e-mail. If I need to read an e-mail concerning the prices of computers as I am buying them,

I would not want a potential customer to see that e-mail.”

Fayaz, Male 37 yrs, Zarqa

In both countries, the negative public visibility of people with disabilities was driven by a combination of traditional beliefs related to the role of disability in society, and generations of excluding people with disabilities from the workplace. The relationship of disability with dependence in Christianity and Islam meant that the individual job-seeker could either be viewed as mystical, as the object of virtuous suffering, or as a beneficiary of “Zakat” or charity (Miles, 1995; Hull, 2003).

“There are the people who think that, being a VI, you should stay at home and read Quran and blessings for others, because being blind, your prayers will be answered [sarcasm]. Because, you know blind people are blessed.”

Heba, Female, 29 yrs, Amman

“Maybe it’s (disability) assumed as a proof from God, like something to test your faith and nothing else (...) there are many people in the streets who talk to you about God and that you could be cured by praying and there is a big need from others to make you part of a religion.”

Armando, Male, 30 yrs, Lima

These beliefs are often extremely important in the ways they translate to the objectification of disability in policy. One of the biggest challenges in policy therefore has been laws around workplace accommodation and diversity. For AT users seeking to enter the workforce, the consequences of this went from a general unawareness of employers in the workplace abilities of people with disabilities to a flat out rejection of the possibility of hiring someone with a vision impairment.

“(The job search) was the worst time of my life. I would prepare a short CV after

I graduated from High School. I would be thrown out of some places by the security. There are others who would give me money as though I am a beggar. He only looks at me as though I am someone in need and a conduit to get to heaven.”

Hassan, Male, 31 yrs, Jerash

The problem of late access to technology due to a lack of institutional investment such as AT through schools or community services is perhaps one of the major elements of policy not adequately addressed in either Jordan or Peru. Respondents noted a significant expansion of aspiration after they started accessing AT, in some sense because it made them more aware of their own capabilities. The lack of AT therefore represents a fundamental capability deprivation, because embedded in this is the structural problem of little or no awareness of AT among the general population, and among employers specifically.

Narratives: Capability Deprivations

One of the most persistent forms of capability deprivations has been the channeling of people with disabilities broadly and vision impairments specifically into certain vocations. In diversified economies, this has often been towards jobs such as lottery sales (Garvia, 1996), physical therapy (de Jong, 2005) or telephone operation (Jose & Sachdeva, 2010). The idea of “channeling” people with disabilities towards certain professions was found to be pushed in both countries as culturally relevant. As studies have indeed found, a range of barriers starting at or exacerbated by the formal education system, contribute to the limitation of opportunities for people with vision impairments, especially when these interact with other institutional barriers around the way social services have traditionally been structured in the specific cultural contexts (Gilson & Dymond 2012).

The ability to universalize disability rights, particularly in choice of vocation, is relevant

here for Jordan and Peru, and potentially for LMICs generally. The discourse of universalism, particularly where a certain set of rights is seen as originating in the West has been problematic in proposing capabilities approaches for various population (Nussbaum, 2001). A range of movements from human rights to women's rights have faced challenges in international forums as being driven by one or another cultural agenda. These sets of concerns are particularly valid given the infantilizing view of disability as representing a motivation for charity and piety among the mainstream population.

“You cannot, as a VI in Jordan, go for a scientific stream; we usually have to go for the literary stream. Even in the universities they do not allow us; the system does not permit us to study anything we want, such as Engineering or IT.”

Asef, Male, 27 yrs, Jordan

“Since I am conscious and adult, since 1998 let's say, since that year they keep training blind people for telephone operators, oh and masseurs; those two things, nothing else. So they are working on this for how many years and they can't imagine that blind people or with low vision can do anything else as professionals other than masseurs and telephone operators.”

Carlos, Male, 42 yrs, Lima

Such channeling extended past the education system into the employment gateway and even the specific functions in a job. This eventually contributed to a greater sense of underemployment among the respondents, as they felt guided to jobs by exigencies more than by abilities or interest. The engineering of individuals towards certain vocations is clear in our research, even among highly skilled AT users. 36 of the 65 employed respondents remarkably held one of three jobs – massage therapy, telephone operation, or school teaching.

However, the spread of jobs also shows a remarkable difference between Peru and Jordan. In Jordan, especially because of the government's role in employing people with disabilities, teaching in the state-run schooling system was an important avenue of jobs, despite the risks of underemployment and workplace stagnation. In Peru, in contrast, telephone operation and massage therapy are the two most common professions. Massage therapy as a category does not exist at all in Jordan. Their employment in a “physical” work reinforced the idea of intellectual work as being outside of the realm of possibilities for people with vision impairments.

“...People think that people with disabilities are better for mechanical jobs. People relate blindness with masseurs, telephone operation, and telemarketing.”

Rita, Female, 41 yrs, Lima

Table 3: Job Distribution – Professions

Country	Gender	Telephone/ Receptionist	Massage therapist	AT -related	Non-profit sector	Professional	Clerical	Teaching	other
Jordan	Male	3	0	2	1	0	0	7	3
	Female	0	0	1	0	1	0	4	0
	Total	3	0	3	1	1	0	11	3
Peru	Male	5	8	1	3	3	0	1	4
	Female	5	2	1	1	3	3	1	2
	Total	10	10	2	4	6	3	2	6

Underemployment had important consequences for the respondents' professional self-fulfillment in the work environment. Learning to use AT led to a greater realization of how separated jobs were from what one is able to do.

"The idea is that instead of getting welfare, you are only getting some money for sitting in the office. I do not need to use it [AT] when I am teaching. You know, you get employed by the Civil Services Bureau on 'humanitarian' basis as it is referred to. Once you are at the job, they do not actually want you to do anything; you do not have real duties at the job."

Ismail, Male, 33 yrs, Amman

We found that 29 of the 50 Peruvian respondents relied on themselves for their job search strategies, whereas only 6 of the 25 Jordanian respondents primarily searched for jobs themselves. In Jordan, there were fairly established routes of job searching, through quotas or institutional connections, and usually to the same few employment options that had grown to have small, long-term populations of employees with vision impairments. The existence of these arguably led to the lack of attention to the challenges that would exist were people with disabilities more evenly distributed throughout the workplace – such as spatial issues like poor access to sidewalks, overcrowded public transit and poor attitudes towards inclusion in transit. None of the reports from the two countries adequately addressed questions around public space inaccessibility, and how that adds to existing social attitudes towards disability, and the channeling away from full economic participation. For instance, respondents reported being disallowed from getting onto public transit since they were assumed to be beggars.

"I live in the camp in Jerash; therefore, there are a lot of transportation mediums I have to take before I get to Amman. Neither the people nor the infrastructure are ready to handle VIs. I leave my house

at 7 am and get to my job at 8:30 am. Throughout these 90 minutes, I am in hell. There are a lot of stations, someone starts to admonish: 'why you left the house in the first place as a VI?' Someone else will try to cut the queue before you. Sometimes, taxis will not allow you on."

Khaled, Male, 31 yrs, Jerash

"For example, a policeman told me 'why do you come alone?', 'because I come from work', 'but you should come with someone'. A policeman is supposed to help you and tell you 'we're going to help you to take the buses and that's it, but no 'why are you out alone? Why do you work? Your parents should help you.'"

Grecia, Female 35 yrs, San Borja

An important area of the discussion on inaccessibility was that of actual workplace access, for blind people. A huge concern was access to licensed AT. Due to the high cost of AT software on desktop machines, piracy was fairly widespread for home use. However, employers were neither comfortable with pirated copies, nor willing to invest in license AT.

"The systems administrator came here and deleted all my screen readers because they said that as we don't have licenses, they didn't want me to have it, so they deleted it. So I said 'how am I going to work,' 'that's not my problem' he said, 'I can install NVDA,' but the NVDA is terrible because it's free it's a terrible version."

Armando, Male, 51 yrs, Lima

Legal requirements for companies to provide an accessible workplace were unclear in both countries and will be an evolving challenge for CRPD implementation. Both Peru and Jordan had quotas for people with vision impairments, but in neither case were quotas entirely filled, nor understood in the spirit of a rights-based option for a population that has been systematically excluded from the workplace. While

in Jordan the NGOs and DPOs were effective in connecting people with opportunities, their actual use in training was very limited. The comparison between the two countries on respondents' place of access to technology is stunning – while only 1 of 25 respondents in Jordan used the NGOs for access to AT, the figure was roughly one-third in Peru where 14 of 50 respondents used NGOs for access, a majority of these being females. The gender aspects of AT and workplace is an important area that needs much further work.

Conclusion

A comprehensive national action plan, incorporating disaggregated statistics as on disability and involving disabled persons and DPOs in its formulation are key elements of a mechanism for implementing the Convention. We have argued here that the narratives of people with disabilities are an important additional aspect of information on disability that is rarely considered in national level data collection. The capabilities approach prioritizes the individual's ability to actualize skills and potential. Prioritizing involvement and the voice of stakeholders is a critical part of this.

Our main proposition in this paper has been to emphasize the importance of a capabilities approach to scholarship on accessibility and access to assistive technology in LMICs by juxtaposing policy developments against the experiences of individuals whose immediate ability to participate in society is impacted by these policies. The CRPD has set the wheels in motion on moving several nation states towards greater social and economic inclusion, but as we see in the cases of Jordan and Peru, there remain weighty challenges in closing the gap between policies on paper and attitudes in the public sphere. While the CRPD pushes for AT for better inclusion in the economy, the realities on the ground need to be understood through the narratives of individuals. Understanding the gap between the potential of independence and aspiration that AT

gives, and the reality of structural disadvantages and employment-related “channelling” that we find in Jordan and Peru can be useful additions to examine multiple layers of capability deprivation in practice. We argue that the same is likely true in varying degrees for many other LMICs starting the process of re-evaluating their disability policy.

The rapidly evolving state of disability and the workplace, particularly with relation to AT development, makes it necessary for policy to constantly adjust itself. The cases of the Takafu and CONADIS represent two very different ways of integrating citizens' voices into existing policy-making structures, but with both countries, no institutional mechanisms existed to create an ongoing public debate that highlights individual voices on issues of accessibility and does so more than just at the points of policy reports.

And though a lot of the narratives we articulate here suggest persistent deprivation of opportunity and accessibility, it is important to note that we were conducting research among people who are assistive technology users – themselves arguably an upper economic layer among people with disabilities who in LMICs may be among the poorest and most deprived within these growing societies. Broad-based incorporation of the range of voices in this space is likely to be one of the biggest challenges to an effective capabilities-based approach to disability policy.

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Book Review

Title: *Both Sides of the Table: Autoethnographies of Educators Learning and Teaching With/In [Dis]Ability*. Disability Studies in Education, Vol 12. Eds. Susan L. Gabel and Scot Danforth.

Editor: Phil Smith

Publisher: New York: Peter Lang, 2013

Paperback: ISBN: 978-1-4331-1451-9

Cost: \$40.95, 277 pages

Reviewer: Steven E. Brown, PhD

I just finished this exciting book. But I would find it exhilarating. After all, I wrote the poem, “Tell Your Story,” in the early 1990s and this book is all about telling—and making sense of—stories.

What is “autoethnography”? “Simply, autoethnography is a kind of self-writing—by which I mean not simply a writing about the self, but a writing of the self—a making and performing of me-in-culture” (p. 16). There are pages more of explanation of what autoethnography is, far too many to summarize here. It is described as political, radical, subversive, strategic, autobiographic, cultural, identity focused, among other perspectives. In this work, it might be considered a way to look at, reflect on, analyze in a multitude of ways (for examples: poetry; seemingly stream-of-consciousness writing; familial deconstruction; and imagined panel) how teaching and learning are impacted, de- and re-constructed by life stories, and how they fit into challenging—and changing—ways we teach and learn.

The book is divided into four sections, with the first and last ones containing four chapters by editor Phil Smith explaining why autoethnography (Ch. 1) and how to use it and how the chapters contained in this book move forward to change the paradigm of teaching and education, especially related to those with disabilities and even more particularly those with disabili-

ties who are in Special Education. Smith also has a chapter in the section titled “Living with Disability—Stories by Labeled People,” called “This Closet,” which is about his own struggles with depression (Ch. 5) and is one of two book chapters written entirely as poems. Another chapter in this section is Elizabeth Grace’s “Autistethnography,” looking at her experiences with education as someone labeled on the Autism spectrum.

The section entitled, “Living Alongside Disability—Stories from Family Members,” describes parenting, being a sibling, deconstructing a family’s dynamics and an eccentric family. Yet, these descriptions do not to justice to these chapters that are personal, exploratory, revelatory and deeply emotional; all the while the authors work to place their stories in the dynamics of education, teaching and learning. In “That’s OK. They are Beautiful Children,” Kathleen A. Kotel, concludes:

“My hope is that all kids play together and go to school together; that there are more open, honest conversations about disability, acceptance and diversity; and that all teachers teach all students. My hope is that when children see people with disabilities, they will have no need to point. That’s the kind of world I want my children to grow up in” (p. 211).

This book belongs in disability studies libraries and courses, but just as importantly, it belongs in all libraries and all courses that address issues of disability, education, or understanding each of those subjects. Kudos to Smith and each author for a challenging, provocative, and engaging book.

Steven E. Brown, PhD is Professor of Disability Studies and Review of Disability Studies Media Reviews Editor at the Center on Disability Studies, University of Hawaii. He can be contacted at sebrown@hawaii.edu.

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Book Review

Title: *Quality of Life and Intellectual Disability; Knowledge Application to Other Social and Educational Challenges*

Editors: Roy I. Brown and Rhonda M. Faragher

Publisher: Nova Science Publishers, New York, 2014

ISBN: 978-1-62948-264-4 (hard cover)

Cost: \$189.00, 418 pages

Reviewer: James G. Linn, PhD

In response to a need to systematically measure the effects of public policy and programs on individuals and communities, social scientists in the 1970s developed quality of life (QOL) studies. In many cases, they were theoretically based, for example, Maslow's Hierarchy of Needs (1954). They generally assumed that quality of life was a multi-dimensional concept and used quasi-experimental designs and quantitative measures that previously had been found to be valid and highly reliable indicators across various populations, for example, life satisfaction. In the 1980s, clinicians/researchers working in the fields of intellectual and developmental disabilities also began to study the quality of life of their patients. They were concerned with how such contextual conditions/variables as poverty, parents' educational level, and ethnicity related to successful interventions and how successful and not so successful interventions impacted individuals with intellectual and developmental disabilities quality of life or personal well being. These studies tended to be small sample, one-time interviews using qualitative and sometimes

quantitative measures. They have become more rigorous over time using mixed method (quantitative and qualitative) designs and validated indicators that allow for meaningful comparison of findings and study replication.

In *Quality of Life and Intellectual Disability; Knowledge Application to Other Social and Educational Challenges*, Roy I. Brown and Rhonda M. Faragher have brought together 17 essays that describe the historical development of the concept of QOL in research on intellectual and developmental disabilities and the wider application of the evolved quality of life framework to policy management and practice, family studies, gerontology, and other issues. The edited book includes essays from scholars in a wide range of disciplines, including disability studies, education, nursing, psychology, social work, and theater, from many different nations (Australia, Canada, Netherlands, Spain, United Kingdom, and United States). The target audiences are clinical researchers, policymakers, and advanced graduate students.

While this book has many excellent contributed papers, several are outstanding for their original contributions to knowledge about QOL and mental disability. Robert Schalock and Miguel Verdugo discuss quality of life as a change agent. They describe how the QOL concept impacted programs and applications in the area of intellectual disability and the wider field of disability studies and how the framework has been useful for planning organization change. In their concluding discussion, they provide six useful guidelines for implementing the QOL framework in research and three more related to organizational innovations. For research, the guidelines are:

- Use a multidimensional perspective in QOL conceptualization;
- For QOL studies use multivariate research designs & methodological pluralism;

- Note cultural and philosophical properties of QOL;
- Validate QOL across diagnostic groups;
- Use personal and family well-being/ QOL as outcome variables;
- Construct QOL theory from empirically validated concepts and hypotheses.
- Partnerships between professionals and families;
- Parent support groups;
- Family therapy programs;
- Respite services.

To apply QOL to organizational change, the guidelines are:

- Use QOL concepts in organizational policies and practices;
- Implement QOL concept to expand human rights;
- Teach QOL concepts in training programs.

Nina Zuna, Ivan Brown, and Roy Brown present a support-based framework to enhance quality of life in families. Their Family Quality of Life Support Based Framework emphasizes Protective and Supportive factors. It is assumed that when these factors are appropriately integrated into services provided to families with individuals with intellectual and/or developmental disabilities, the services will have better outcomes for family quality of life. Some of the salient Protective factors include:

- Mother's sense of coherence;
- Family members' orientation to familism;
- Parents' positive perceptions of their children;
- Family health status;
- Family financial status.

Among the key Supportive factors are:

- Accessible Disability specific programs;

Trevor Parmenter focuses on the link between social inclusion and a good quality of life for persons with intellectual and developmental disabilities. He maintains that creating a positive self image is essential for a good quality of life. Further, for him, it is through the process of social inclusion in which persons receive positive feedback for successfully performing various social roles that they develop a well grounded self-esteem. While the connection between inclusion and a good quality of life for persons with intellectual and developmental disabilities is clear to most professionals working in the field, Parmenter observes that the way forward to greater inclusion is obstructed by the dominance of market ideology. This belief system, which prevails in most industrialized societies and is growing globally throughout the developing world, tends to assess social initiatives, including those programs for persons with intellectual and developmental disabilities, by their economic impact.

Further, individual worth is valued by the person's level of contribution to the community. This is a challenge to the self-esteem and perceived well being of vulnerable people who throughout their lives may be dependent on various social supports.

Quality of Life and Intellectual Disability: Knowledge Application to Other Social and Educational Challenges is appropriate to a targeted audience of clinical researchers, policy makers, and advanced graduate students. It contributes to existing knowledge, particularly through the chapters on Quality of Life as a Change Agent, Family Quality of Life in Intellectual and Developmental Disabilities, and Inclusion and

Quality of Life. Overall, the articles included in this edited book are interesting because they include social observations and related professional experiences of scholars from many different countries. However, priced at \$189, it may be well beyond the budgets of most intended users. Further, this reviewer found the font small and, therefore, somewhat difficult to read. Consequently, it may not be accessible for potential readers with vision impairments.

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Book Review

Title: *Mad Matters: A Critical Reader in Canadian Mad Studies*

Editors: Brenda A. LeFrançois, Robert Menzies, and Geoffrey Reaume

Publisher: Toronto, Ontario, Canadian Scholars' Press Inc., 2013

ISBN: 978-55130-534-9

Cost: Softcover, 394 pages, \$49.95 CAD

Reviewer: Shulan Tien, PhD Candidate, Fu-Jen University, Taiwan

Grounded in the context of 50 years of the Canadian psychiatric survivor movement, *Mad Matters: A Critical Reader* in Canadian Mad Studies, according to the editors, is the first book officially declared as Mad Studies in Canada. This anthology illustrates what has happened, what is happening, and the future challenges for this radical mental health movement, or Mad movement. It is about, and for, the psychiatrically oppressed who are searching for systemic social change, critical pedagogy and community

organizing. The authors reflect on the progress of the psychiatric survivor movement while remaining vigilant about pitfalls, co-option and appropriation, and attending to the dynamics and tensions inside the movement and with other social struggles, such as anti-colonialism, class, immigration, and gender/sexuality.

Early in the psychiatric survivor movement, authors like Burstow & Weitz (1988), and Shimrat (1997), who remain active in advocacy, updated their critiques regarding the discriminating nature, insanity, violence and abuse of psychiatric treatment that still exists today (Chapters 10, 11). Those who admire Canadian Community Mental Health Care, developed after the deinstitutionalization of the 1970s, will probably be shocked by the reality in British Columbia that Shimrat exposes. The following quotes suggest this reality: "Community mental health praxis results in a vast number of human lives primarily characterized by cognitive impairment, chronic illness and, most ironically, social isolation far more severe than that suffered in the bad old days of long term institutionalization....on the other hand, institutionalization sets in very quickly" (p. 154); "it never lets you go" (p.148), and "her outpatient committal order obliges her to subject herself to this ongoing damage and humiliation, on pain of re-incarceration if she fails to comply." (p.155)

As an insider, psychiatrist Warne, (Chapter 15) discloses that psychiatry self-claiming as science is actually based on the fundamental delusion of "the equation of mental experiences with physical illness" (pp.192-193). With that delusion, which Warne believes, psychiatrists justify treating Mad people like dangerous, different beings. This empowers psychiatrists to intervene in people's lives as healing professionals, depriving mad people of their human rights.

Apart from the macro scope described in the preceding paragraphs, the narratives of Pole and Ward; Lee; and Liegghio (Chapters 6-8) provide personal, intimate, and emotional stories as well

as insightful analysis of modern mental health practices. Pole and Ward challenge the modern, western “science of bereavement” (p. 91) that pathologizes and colonizes the grieving experiences. They encourage readers to embrace “Mad grief”, while seeking to start a conversation, not about how to progress, recover, and ‘get over’ pain and loss, but how to ‘get under’ it, feel it, and claim it as it comes” (p. 95). As a self disclosed psychiatric survivor of a Westernized Korean mental health system, Lee empathizes with other survivors’ autobiographical stories, and voices survivors’ perspectives towards psychiatry. As a daughter caring for her dying mother, Liegghio depicts how psychiatry denies humanity “by a particular type of violence that targets and denies personhood” (p. 123), disqualifying a person as having legitimate knowledge.

Situated in a critique of capitalism, colonialism, racism, patriarchalism, liberalism and neo-liberalism, the first three chapters of *Mad Matters*, describe the legacy of the Canadian survivor movement since the 1970s.

Through this book, the complexity and evolution of politics manifested in the language can be traced: the mental patient liberation movement, consumer/survivor/ex-patient (c/s/x) movement, mad/Mad movement, survivor movement, and anti-psychiatry movement. For example, in Chapter 4, clarifying the commonality and differences among the anti-psychiatry movement, survivor movement, and mad movement, Diamond raises the issue of the limitations of specific identities and trying to bridge the differences in a “anti-sanist community” (p. 73). While articulating the nuances of language, Burstow (Chapter 5) urges us not to “slide into liberalism” which beds individualism and consumerism. She states, “the (psychiatry) regime in question can accommodate, provide space for celebration and consultation, offer minor concessions, and yet not appreciably change anything” (p. 85). Gorman (Chapter 19) points out the progressive and conservative political possibilities of Mad identity, discerned by whether

it diverts from the historical roots of anti-oppression, class struggle, anti-racism and anti-colonialism. The latter, for example, could ignore the force of global capitalism and box itself in an intersectional perspective of gender and disability. According to Gorman, it is based on “an essential ontology”, and it “could reproduce a white, Western Mad subject” (p. 270).

This book also illuminates current developments and pressing issues. For example, peer support has a long history and is the foundation of the psychiatric survivor movement.

However, institutionalized or certified peer support workers are a rather new, and tricky, trend of occupation. They are situated in the margins of the system, being divested based on the mental health regime’s preference. Fabris (Chapter 9) contemplates “when peer support is conceived as yet another brand of mental health product” (p.131), how or whether it is possible to maintain an advocacy, self-help role in promoting systemic change.

Another example, soaring since the 1980s, is the recovery paradigm, having evolved along with the mental health institution and the survivor movement, encompassing diverse interpretations, practices and political implications. According to Morrow (Chapter 23), it is “poised to either disrupt biomedical dominance in favor of social and structural understanding of mental distress or to continue to play into individualistic discourses of ‘broken brains’, ‘chemical imbalance’ and ‘self-management’” (p. 323).

Many countries have promoted some kind of mental health literacy (MHL) based on the biomedical model, which harbors a problematic anti-stigma campaign. According to White and Pike (Chapter 17), the campaign of MHL in Canadian mainstream society joins seamlessly with a business model and upholds a single value system of biomedical ideology, “transcribed into a series of units packaged neatly as measurable outcomes, and deliverables” (p.243). Voronka (Chapter 22) analyzes the materially oppressive

class and racial issue of youth being consciously shifted from criminalization to pathologization. This is done by focusing on “the undisciplined bodies and damaged mentalities of ‘at-risk youth’” (p.267). These problematized children and youth internalize those notions, and “through the ‘psy’ disciplines, come to understand their trouble in individualized, often biomedical frameworks that decontextualize the role that structural oppressions play in the constitution of their personhood” (p.318-319).

On the bright side, Reville and Church (Chapters 12-13) provide an example of infiltration that the Mad movement has been developing in academia through Mad courses, creating a revolutionary pedagogy by introducing the perspective of the Mad, and creating various platforms to physically bridge the Mad community and academia.

Mad Studies/movement shares a long, broad historical and social struggle with many other movements, especially the disability rights movement and Disability Studies. It adopts human rights, independent living, self-determination, and human diversity campaigns from broader trends, and has developed specific interpretations and tactics further expanding the diversity and potential of the disability community. Throughout the book, *Mad Matters* magnificently and abundantly covers the texture and importance of intersectional threads, to include gender, race, aboriginality, immigration, sexuality, geographical region, and class. There are four chapters specifically dedicated to human rights (Warne, Chapter 15; Wipond, Chapter 18; Costa, Chapter 14 and Finkler, Chapter 15).

Regretfully, this book does not include an important, unique and timely (in this pro-entrepreneurship era) development in Ontario, Canada called the psychiatric survivor-run business (Church, 1997, 2004) approach. Those businesses provide real jobs, real pay and are run by survivors. In tackling pressing disability em-

ployment and peer support issues, this approach will fit well in a future edition.

This book is quite expensive for a community worker or student, but is surely a must for university and public libraries. I highly recommend it to interdisciplinary scholars, university students, community activists, policy makers, and practitioners in the mental health system and legal fields. It is a crucial read for anyone interested in grasping a sense of the contemporary Canadian Mad movement, or wishing to gain new reflections by comparing the experiences of Canada to their own contexts.

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- Shulan Tien, PhD** Candidate in Psychology at Fu-Jen University, Taiwan, has been working as an instructor, consultant, activist and community organizer in disability, not just based on a rights approach, but also about the social meaning of disability itself, the political constructions that produces/defines/perpetuates it; and the social relations among and around so-called people with disabilities. Between 2008 and 2010, she went to Toronto, Canada to study the psychiatric survivor movement.

Film Review

Title: *FIXED: The Science/Fiction of Human Enhancement*

Filmmaker: Regan Brashear

Production Company: New Day Films,
Blooming Grove, NY

Cost: \$325, Educational DVD; \$375,
Institutional Streaming (3 years)

Reviewer: Amanda McLaughlin

What does the word “disabled” mean to you? Google says it pertains to “having a physical or mental condition that limits movements, senses, or activities.” So, if it were possible to eliminate these limitations by simply taking advantage of technology, robotics, or medication, would disability disappear? Would we want that? What if adaptive technologies, such as leg prostheses, used as adaptations for people with disabilities to have “normal” functioning, actually allowed them to surpass average ability, for example, to become taller than an original height, or to run faster? Who, then, would be “disabled?” Human enhancement technology is defined as, “Using medicine, or surgery, or other kinds of medical technology not just to cure or control illnesses but rather to enhance, or improve, human capacities and characteristics” (Elliott, 1998). The creation of these technologies offers solutions to what have been seen as “problems” for centuries. But with every solution arises a new set of issues. Will we slow down long enough to consider the end result?

FIXED: The Science/Fiction of Human Enhancement asks this question, offering an unbiased journey towards understanding the human reaction to disability and our need to “fix” that which creates disability. Researchers and scientists from every corner of the world are currently developing technology to eliminate impairment and enhance the human body in ways many of us could have never imagined. *FIXED* shows us the often radical technological innovations that allow us to transition from what was previously

allocated to science fiction, to our current reality, and its potential ramifications.

This probing documentary opens with a family talking about what enhancements they would prefer if given a choice. Their answers, like that of many people, reach back to childhood superhero desires. It is not surprising to want to fly, have super strength, or enhanced vision or hearing. In a society that glorifies all that is “super,” it is hard to imagine not wishing for something to make you better than your competitor, something to push you beyond your limits, making you enviable to those around you. Is it merely human to want more, to crave better, to desire bigger, stronger, and faster? We are undeniably competitive creatures, but at what cost?

The viewer is shown a barrage of clips of various body enhancement examples: a bionic arm for a soldier, a mechanical eye, prosthetic legs for a sprinter, and hearing aids. We are in the midst of burgeoning adaptive and assistive technologies. It is around us all the time, sometimes in an unavoidable flashy display and other times hidden from the naked eye.

John Hockenberry, a journalist with a spinal cord injury and a Distinguished Fellow at the Massachusetts Institute of Technology’s (MIT) Media Lab, talks of the importance of people with disabilities in advancing these technologies, as they “are on the front lines” trying them out. They can offer a wealth of information about human/machine collaboration because they are so accustomed to working with machines in their everyday lives. When asked about how he was able to be so successful, despite his disability, he responds:

“It is normal to do what I’ve done. It is absolutely. This [people with disabilities] is part of the human story. Disability, improvising in the face of obstacles and change; I think this is what human beings do. This is why there are 6 billion of them on the planet, because we are very good at this sort of thing.”

Next, we meet Hugh Herr, Engineer and Director of MIT's Biomechatronics Lab. While mountain climbing as a young man, he survived a storm that left his legs badly frostbitten. Both legs were amputated due to his injuries. One year after he lost his legs, he was able to climb better than he was before the accident due to prostheses he designed. He says:

"I no longer viewed my body in the way society viewed it, as being broken, as being disabled, as being crippled. I started to view, not my biological body in that way, but the artificial part of my body, that it was crippled and disabled. As a young man I imagined a world, a future in which technology so advanced that I could largely eliminate disability in my own life, extending that to other human beings to eliminate disability across society."

Herr focused on developing wearable robotic systems that would augment human physical capability. He hopes to assist those that have had limb amputations, and those with intact physiologies, to surpass their current abilities.

Gregor Wolbring is a Biochemist and Ability Studies Scholar at the University of Calgary in Canada. We meet Gregor as he prepares himself for the day. He lives in a modest house in Calgary. He chooses to crawl when in his apartment, instead of using his wheelchair. He explains that crawling may be seen as demeaning to some, but to him is simply a way to be self-sufficient. He has a likeable softness to him but it is very clear that he has unshakable conviction about his work and his stance on ableism. He explains:

"[There is the idea that] the only way you can gain respect is to show you are superior to someone else. This is ableism. Ableism is our obsession with certain abilities and the treatment of people that don't have these kinds of abilities."

Patty Berne, Project Director of Disability and Eugenics at the Center for Genetics and So-

ciety in Berkeley, California, brings the viewer into her home. She is struggling with getting someone to come over and repair her wheelchair. It is obvious that this is an ongoing battle. She talks about how funding to ensure those with disabilities have their basic needs met - for example, that everyone who needs a functioning wheelchair has one - should be the priority. Using that money to create advanced technology that will not be used by the average person with a disability, seems wasteful to her. She goes further, talking about how we could instead create a more accessible environment, and how far we have to go before our world is one of complete inclusion. Patty says:

"People look at disability as a personal tragedy, as something located in the body. For example, someone would see me and say, you have a problem because you cannot walk and so you have different needs so that you can fit in. But from the disability rights perspective, the problem is not in my body, but the problem is in the social disregard and a lack of integration of people with disabilities."

The film's creator, Regan Brashear, has been working on labor, race, youth, LGBTQ (Lesbian, Gay, Bisexual, Transgender, Queer), and disability issues for over 20 years through documentary film, union organizing, community forums, and grassroots activism. When asked why she was interested in making the film, she states:

"Quite simply, as a person with a disability, I wanted to make a film that seriously engages with both disability and technology in new ways and provokes questions about what human enhancement technologies mean for you and me. What are they? Will they improve our world? Who will they benefit? And at what cost?"

By using an entertaining and creative mixture of dance footage, as well as archival and interview footage, FIXED forces the viewer to consider notions of "normal," to contemplate

our relationship to our bodies and to examine what being human means in the modern age.

FIXED is a useful tool to arouse discussion on the direction of adaptive technology, what it means to those with and without disabilities, and the moral implications of the decisions we make having to do with our bodies. This documentary has a social science, disability studies, occupational therapy, engineering, medicine, nursing, and fine arts appeal.

Amanda McLaughlin is an editorial assistant at the Center on Disability Studies at the University of Hawaii, Manoa. She holds a Bachelor's Degree in Media Communications with an emphasis in Film. You may contact her at amandat2@hawaii.edu.

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Editor's Note: The information for this section of RDS is provided by Jonathon Erlen of the University of Pittsburgh. A full list of disability-related dissertation abstracts may be found at: <http://www.hsls.pitt.edu/guides/histmed/dissertations/>

1. *Speaking for themselves: The blind civil rights movement and the battle for the Iowa Braille School*
Miller, B. ProQuest Dissertations & Theses, 2013. [PhD Dissertation] United States: Iowa: University of Iowa, 2013. Publication Number: 3595125.
2. *Shadows of perfection: Illness, disability, and sin in American religious healing, from the Civil War to World War I*
Hines, T.S. ProQuest Dissertations & Theses, 2013. [PhD Dissertation] United States: California: University of California, Santa Barbara, 2013. Publication Number: 3596156.
3. *Faculty attitudes toward students with intellectual disabilities in postsecondary educational settings*
Fekete, D. ProQuest Dissertations & Theses, 2013. [PhD Dissertation] United States: Michigan: Wayne State University, 2013. Publication Number: 3594663.
4. *Experiences of Asian Indian families with Special Education and disability-related services in America*
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5. *College students on the autism spectrum: Social experiences and self-disclosure*
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6. *Attitudes toward students with disabilities at Notre Dame University, Lebanon*
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7. *Identity formation among ethnic minority men following spinal cord injury*
Holden, S. ProQuest Dissertations & Theses, 2013. [PhD Dissertation] United States: California: University of La Verne, 2013. Publication Number: 3574223.
8. *A critical study of Black parents' participation in special education decision-making*
Freeman-Nichols, T. ProQuest Dissertations & Theses, 2013. [PhD Dissertation] United States: Virginia: The College of William and Mary, 2013. Publication Number: 3574196.
9. *The opinions of administrators of languages other than English regarding American Sign Language as an equivalent language*
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10. *Authentic membership: The experiences of two students with hearing loss in instrumental music*
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11. *A portrait of being artistically talented with Asperger's Syndrome: A retrospective case study*
Johnson, R. ProQuest Dissertations & Theses, 2013. [PhD Dissertation]
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12. *Imperial injuries: Race, disease, and disability in North American narratives of resistance, 1908—2006*
Sibara, J. ProQuest Dissertations & Theses, 2013. [PhD Dissertation]
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13. *The experience of living with chronic illness: A heuristic study*
Pogge, S. ProQuest Dissertations & Theses, 2013. [PhD Dissertation]
United States: Texas: Texas Woman's University, 2013. Publication Number: 3598478.

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The Center on Disability Studies is the umbrella for some 25 funded projects. It originated as the Hawai'i University Affiliated Program (UAP) funded by the Administration on Developmental Disabilities of the U.S. Department of Health and Human Services. It was established in 1988 as part of a network of over 60 UAP's in the United States. It is now a University Center for Excellence in Disability Education, Research, and Service.

Although core funding for the Center is provided by the Administration on Developmental Disabilities, other federal and state funds are provided by the Maternal and Child Health Bureau of the U.S. Department of Education, various other programs in the U.S. Department of Education, the University of Hawai'i, and the State Planning Council on Developmental Disabilities.

The activities of the Center for Disability Studies extend throughout the state of Hawai'i, the mainland United States, and the Pacific region with funded projects in several initiative areas including intercultural relations and disability, mental health, special health needs, Pacific outreach, employment, and school and community inclusion.

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