

Editorial

RDS Commitment to Honoring Diversity

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RDS Editor-in-Chief

In March, 2017, I authored an RDS Editorial titled *Disabled Lives Matter*. The Editorial was inspired by a 2017 report released by the Southern Poverty Law Center on how the 2016 Presidential Election impacted school climate for marginalized people including people of color, religious minorities, women and LGBTQ people. The survey revealed that a shocking 90% of respondents saw a negative impact on school climate, but neglected to offer up “disability” as a possible reason for marginalization. The larger point of my editorial was to emphasize that disability – like race, religion, gender, and sexuality – is a critical category to consider when pondering such questions, yet it is often overlooked as the very framing of this survey revealed. However, when the editorial was recently re-released it received a slew of criticism on social media. Especially given the title of my editorial, critics argued that it seemed to rank these various social categories as if some mattered more than others and also seemed to ignore simultaneously experienced disability, race, gender, sexuality, etc. RDS Editorial Board member Jenifer Barclay summed up this criticism pointedly when she wrote:

“[It is] problematic to appropriate the phrase ‘Black Lives Matter,’ especially given the significant backlash and actual violence that people who use that phrase have experienced in recent years. For instance, people peacefully protesting against police violence who invoke the phrase ‘Black Lives Matter’ have been met with militarized police, SWAT forces, tear gas, and physical abuse (e.g. Ferguson, Baltimore). Others, like Colin Kaepernick, are blackballed from their professional livelihoods. Conservative news outlets and neo-Nazis/white supremacists alike routinely frame ‘Black Lives Matter activists’ as angry, lawless, irrational people of color who ‘hate’ white people. Given these realities, I can understand - and agree with - the frustration of those who criticized the editorial and interpreted the (mis)use and distortion of that phrase as insensitive.”

In the wake of criticism about the Editorial, I issued an apology for any offense that it may have caused some readers, including the following statement:

“These are very difficult times for all of us who are personally and professionally impacted by social justice issues. I as much as anybody understand the power of language to convey meaning, and the importance of maintaining the sanctity of the meaning that words convey. My goal as Editor of an academic disability studies journal is to further understandings of diversity.”

With these words in mind, I would like to take the time to reaffirm my commitment, and RDS’s commitment, to representing and respecting through the promotion of Disability Studies, the richly diverse community of individuals with disabilities and their allies.

First, a reminder about ways RDS has already demonstrated our commitment to diversity:

- RDS was founded in 2003 with a mission to “provide an international forum for people with disabilities, academics, professionals, artists and creators from all backgrounds and expertise to express ideas relevant to disability studies and people with disabilities.”
- The RDS Editorial Board, Manuscript Review Board and core staff hail from multiple countries and disciplines and have diverse cultural identities.
- RDS has published over 530 authors from 43 countries around the world.
- RDS publishes articles on a wide range of topics. Some examples of past titles around topics of diversity include *Unsettling the Resettled: An Intersectional Analysis of Autism in the Somali Diaspora* (v14i1), *Changing Disability Status of Immigrants in Australia - Three Cases* (v132), *Strategies to Create a Culturally Responsive Learning Environment* (v11i4), *Precarious Inclusions; Re-Imagining Disability, Race, Masculinity and Nation in My Name Is Khan* (v10i2), *Performing the Pain: Opening the (Crip) Body for (Queer) Pleasures* (v6i3) and *Physical Disability, Gender, and Marriage in Jordanian Society* (v10i1&2).

But of course, we can do better! Here are some of the ways RDS is seeking to remain on the cutting edge of Disability Studies by improving our commitment to diversity now and in the future

- The RDS Editorial Board is working on a permanent statement and revised author guidelines reaffirming our commitment to language that respects diverse identities, including gender neutral language, and established and evolving understandings of respectful language.
- Led by Forums Editor Jenifer Barclay and Research Editor Mary Jean Hande, RDS will publish 2 forums focused on intersections between disability, diversity and marginalization (target publication dates v15i3, Sept 2019, and v16i1, March 2020). One forum will be focused on these themes within academia and the other within social justice movements.
- RDS is launching a student internship program, to be pilot tested this summer, with a particular focus on recruiting a variety of individuals with disabilities who are interested in gaining experience in academic publishing.
- In order to ensure that work published in RDS is accessible to all, RDS will transition to entirely Open Access in September, 2018.

We look forward to your contributions to RDS as authors, reviewers, readers, and yes, critics. It is essential that those of us involved in Disability Studies think deeply about the complex relationship between power and injustice and embrace a diversity of experiences and perspectives even if they contradict our own. This will ensure that Disability Studies remains vibrant and relevant for years to come.

Forum Introduction

The Crip, The Fat and The Ugly in an Age of Austerity: Resistance, Reclamation and Affirmation

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Welcome to this special forum, *The Crip, The Fat and The Ugly in an Age of Austerity: Resistance, Reclamation and Affirmation*. Our original desire in putting out this call was to critically explore the processes and politics of austerity upon diverse and marginalized embodiments in neoliberal and advanced capitalist times. Global austerity has a far reach, often into, around, behind, beyond and alongside the body. Global austerity routinely categorizes body-minds[i] in terms of productivity, value, cost, ability and aesthetics. Body-minds are positioned vis-a-vis global austerity as a site for social order, economic possibility, progression, and big business. Whereas “[a]n able body is the body of a citizen; deformed deafened, amputated, obese, female, perverse, crippled, maimed and blinded bodies do not make up the body politic” (Davis, 1995, pp. 71–72). In devising this forum, we yearned for space to contemplate the aesthetics, experiences and the reification of body-minds - how capitalism makes sense of and shapes body-minds; the ways in which austerity both marks and produces bodies and selves, and the means through which these are further shaped by disability, race, class, gender, age, size, sexuality, and nation. Although we explore aspects of these in our own work (Liddiard, 2018; Slater, 2015), we wanted to create a space to connect with others and think about diverse and marginalized embodiments in austere times. In this introduction, we story the process through which we put the issue together, from our original decision making and putting out the call, to supporting authors to revise their contributions. We do so because we feel it’s a fitting way to speak to the inclusions and exclusions made in this forum. At the same time, we feel it offers a broader commentary as to the “state” of global disability studies today.

Why the Crip, the Fat and the Ugly?

We could have chosen to title this forum differently. From our interest in bodies and embodiment, ‘the politics of embodiment in austere times’ or ‘diverse embodiment in austere times’ would have perhaps sufficed. Yet, whereas with ‘diversity’ comes liberal connotations of tolerance and ‘progression’ (Conrad, 2014), crip, fat and ugly are provocative, jarring terms which unsettle dominant cultures. As Nancy Mair writes in relation to naming herself a cripple: ‘perhaps I want them to wince’ (as cited in Clare, 1999, p. 82). Furthermore, crip and fat in particular come with certain histories and relationships; not just to academia, but also to arts and activism. Sandahl (2003) highlights that crip was being used in disability arts and activism prior to being taken seriously within academia. Indeed, crip is as much about “self-identified crips in the street - taking sledgehammers to inaccessible curbs, chaining

wheelchairs together in circles around buses or subway stations, demanding community-based services and facilities for independent or interdependent living” as it is about theorising the disabled body within culture (McRuer, 2006, pp. 33–34). We also chose *crip* for its relationship to *queer*, as Clare (1999) puts it, “[Q]ueer and cripple are cousins: words to shock, words to infuse with pride and self-love, words to resist internalized hatred, words to help forge a politics” (p. 84).

Similarly to *crip*, to claim *fat* is to reject its more liberally accepted euphemisms (‘plus-sized’, ‘big boned’, ‘curvy’) and pathologizing medical definitions (‘obese’, ‘morbidly obese’, ‘overweight’). *Fat studies* shares some ontological ground with *crip theory* (and indeed *disability studies* more broadly): both are skeptical of dominant social, cultural and political, largely medicalized beliefs about what bodies should do and be (Brandon & Pritchard, 2011; Cooper, 1997; Rothblum & Soloway, 2009). Furthermore, the growing discipline of *fat studies* is entangled with diverse *fat arts* and activist endeavors (Cooper, 2016). In her monograph, *Fat Activism*, one of Cooper’s (2016) participants describes *fat activism* as “being a response to the negative shit about fat. Challenging discourse, protesting stereotypes, countering fat hate, refusing to accept things, speaking truth to power, rejecting moral discourse concerning fatness, repudiating injustice” (p. 52).

In this forum we wanted to bring together the academic, the activist, the artistic and the lived to consider, critique and challenge ‘negative shit’ about what body-minds should do and be within contexts of austerity. *Crip* and *fat* allowed us to do this. We were also interested in centering the forum around a third term, ‘ugly’. Whereas *crip* and *fat* are increasingly theorized within academia and used for activist purposes, *ugly* appears relatively under-discussed in academia and/or activism, and much less identified with than *crip*, *fat* (or *queer*). Within *disability studies*, discussion of *ugly* appears mainly in the context of the American Ugly Laws which, in the late 19th and early 20th century, stated that “any person who is diseased, maimed, mutilated or in any way deformed so as to be an unsightly or disgusting object, or an improper person to be allowed in or on the streets, highways, thoroughfares, or public places in this city shall not therein or thereon expose himself to public view, under the penalty of a fine of \$1 for each offense” (Chicago City Code, 1881, as cited in Schweik, 2009, pp. 1–2). In her book, *The Ugly Laws: Disability in Public*, Schweik (2009) highlights that the ugly laws were not solely about disability, but reinforced gendered, classed and racialized understandings of bodies in public space. In a rare example calling for a reclamation of the ugly, Mingus (2011) understands ugly as a way to find coalition between social movements when she writes that moving towards the ugly “moves us closer to bodies and movements that disrupt, dismantle, disturb. Bodies and movements ready to throw down and create a different way for all of us, not just some of us.” She goes on to theorize the ugly as such:

“The magnificence of a body that shakes, spills out, takes up space, needs help, moseys, slinks, limps, drools, rocks, curls over on itself. The magnificence of a body that doesn’t get to choose when to go to the bathroom, let alone which bathroom to use. A body that doesn’t get to choose what to wear in the morning, what hairstyle to

sport, how they're going to move or stand, or what time they're going to bed. The magnificence of bodies that have been coded, not just undesirable and ugly, but un-human. The magnificence of bodies that are understanding gender in far more complex ways than I could explain in an hour. Moving beyond a politic of desirability to loving the ugly. Respecting Ugly for how it has shaped us and been exiled. Seeing its power and magic, seeing the reasons it has been feared. Seeing it for what it is: some of our greatest strength" (Mingus, 2011).

Mingus' (2011) essay is in part a call to celebrate those that have been told they don't fit, are wrong and are not good enough. Yet, she also asks us to nurture, rather than to reject, the ugly in ourselves in order to ally with other social movements. In her piece, *NoBody's Perfect: Charm, Willfulness and Resistance* (in this forum), Maria Tsakiri draws on Tobin Siebers' term, disability disqualifier, describing how disability as deficiency is subsequently used to disqualify (or subordinate) other social groups. Siebers (2010) uses the devaluing of femininity to explain: "[b]eneath the troping of femininity as biological deficiency lies the troping of disability as deficiency" (p. 24). Moving towards the ugly is arguably a way to resist the disqualifying of disability, and through such resistance, refuse to disqualify other forms of marginalization.

Perhaps moving towards the ugly is what Cooper (1997) was doing in her article, *Can a Fat Woman Call Herself Disabled?* Here she explores similarities and differences between fat and disabled lives. In doing this, she questions the ableism, and therefore distancing from disability, within 'size acceptance' communities. How many fat people would want to claim disability? Similarly, she wonders about the fatphobia within disability movements. Will disabled people reject fat people through buying into the discourse that fatness is self-inflicted? Perhaps too the queer crip artists in Sandahl (2003) are moving towards the ugly as they queer the crip and crip the queer: "queering critiques and expands notions of what it means to be crippled, and crippling critiques and expands notions of what it means to be queer" (Sandahl, 2003, p.37). And maybe moving towards the ugly is what disabled woman of colour and activist, Vilissa Thompson, was doing when she created #disabilitytoowhite to de-centre and call out the whiteness of disability activism and studies? Or what Clare (1999) is doing when he considers the entwined racism and ableism of the freak show and eugenics movements? Like these authors, and following Mingus, we wanted to use this forum as a space to think about overlapping oppressions and coalition, whilst continuing to explore Mingus' take on 'the ugly,'

What Was Left Out

From our call, we received a series of insightful papers. However, despite the fascinating analyses offered by potential authors, we were also captured by what was left out of these contributions. To clarify: how had authors engaged with our call for papers? Why were some themes markedly more popular than others? What had been omitted and why? What were our original expectations?

Initially, we very were surprised that although authors engaged in exciting ways with issues of bodies and embodiment, austerity as a focus fell away and was paid far less attention. As editors, we (Kirsty and Jen) are both situated within England, and British Disability Studies. Our own experiences of austerity are very much rooted in overt and harmful discourses of scroungers, spongers and skivers and a drain on the welfare state which infiltrate everyday life (as discussed by Sandle, Day and Muskett, this forum). Furthermore, Disability Studies in the UK has its roots in a Marxist materialist approach to understanding disabled people's oppression, meaning that the academic home of UK Disability Studies is social policy and sociology departments - an apt place, perhaps, from which to explore austerity. On the other hand (and maybe for similar reasons), when wanting to explore how disability intersects with other forms of oppression - race, gender, sexuality and so on - we often find ourselves looking to colleagues in North America (e.g. Brown, Ashkenazy, & Onaiwu, 2017; Clare, 1999, 2017; Erevelles, 2011; Kafer, 2013; Mingus, 2011), Australia (Soldatic & Meekosha, 2014; Dowse, 2009) and the Global South (Chataika, 2018; Ghai, 2014; Grech, 2015). Indeed, our original call didn't cite any UK Disability Studies academics, but was rooted in the kinds of cultural studies approaches more akin to North American Disability Studies. We were therefore left wondering: was the overlooking of austerity a result of disciplinary difference? Or does a preoccupation with austerity lie with our geographical location as scholars emerging from Britain and, in particular, British Disability Studies? Is terminology an issue? Are we more aware of austerity politics and lexicon because of our own context?

Moving forward, although potential contributions discussed both fat and crip lives, we also noticed quickly that there was little explicit focus on theorizing the ugly. We wondered why this was: in an age of body modification and global normative aesthetics, perhaps there is not yet space to reclaim/discuss ugly? Exploring his own ease with crip, queer and gimp, but unease with freak, Clare (1999) reminds us that reclaiming words is complicated. Clare's discomfort with freak lies in the continued presence of the freak show. Although freak shows may not exist in their most commonly imagined form, he argues that they still exist within all places that disabled people are stared at: medical institutions, bus stops, welfare assessments. Indeed, two authors in this forum discuss the surveillance of disabled people's lives through classrooms, psychiatric institutions (Benham) and technologies of the quantified self (Schaffzin). For Garland-Thomson (2002), staring at disabled people emerges from "a culture [where] we are at once obsessed with and intensely conflicted about the disabled body. We fear, deify, disavow, avoid, abstract, revere, conceal, and reconstruct disability – perhaps because it is one of the most universal, fundamental of human experiences" (p. 57). The difference between modern day and traditional freak shows, Clare poses, is that disabled people being stared at today have less control today than some disabled people may have had in (historical) freak shows. Perhaps ugly is as, if not more, uncomfortable than freak: only denoting responses of shame, disgust, and an affective reading of the body. Through global austerity the crip, the fat *and* the ugly are typically Othered and denigrated bodies, identities, minds and selves, implicated and co-constituted by one another (Bergman, 2009; Kafer, 2013). Within a context of coloniality, transnational capitalism, patriarchy, cissexism and

white supremacy, the Crip, the fat and the ugly are rendered unintelligible (Butler, 1999), made in/visible (Sandahl, 2003) and vilified locally, nationally, and globally. Does global austerity, with all the precarity and violence it brings, make reclamation of largely unclaimed words too risky?

Inclusions and Absences

Rather than try to answer the questions that we pose above, we leave them there to ponder, in relation to international and cross-cultural connections in global disability studies. Perhaps, one day, they themselves can frame another special issue or forum. Furthermore, it is important to highlight that our musings are in no way a criticism of the wonderfully eclectic range of submissions that we received, and which we proudly publish in this forum. That said, there are marked absences within the forum that need to be acknowledged. The contributions selected offer limited engagement with issues of race, queerness and fatness. Our calling for and curation of contributions has produced these omissions, and for that it is important we acknowledge their absence by calling this out, here and now, while also staying mindful that these absences *contain* the theoretical possibilities of this Forum. Let's take a moment now to consider the key contributions that embody this forum.

In *Working to Feel Better or Feeling Better to Work?: Discourse of Wellbeing in Austerity Reality TV*, Rowan Sandle, Katy Day and Tom Muskett interrogate the entangled representations of wellbeing, work and welfare under UK neoliberal austerity. Their arguments take place through an analysis of what has come to be known colloquially as 'austerity porn' or 'austerity reality television'. The authors argue that the cultural economies of austerity construct a 'good' welfare recipient as self-reliant, independent and working towards waged-work. In contrast, those particular bodies, minds and selves unwilling or able to benefit through waged-work are positioned as lazy and unnecessarily dependent on the welfare state. Individuals are therefore held accountable for any suffering, rather than the life-threatening context of austerity. Offering the deepest and most focused analysis of austerity within this forum, Sandle, Day and Muskett's paper leads us to ask, how does one reclaim, resist and celebrate diverse embodiments with the backdrop of these harsh realities because, as Clare (1999) reminds us, "[W]ithout pride, individual and collective resistance to oppression becomes nearly impossible?" (p. 107).

In *NoBody's Perfect: Charm, Willfulness and Resistance*, Maria Tsakiri begins to answer our call for resistance, as she examines representations of the disabled body in documentary film-maker Niko Von Glasow's *NoBody's Perfect* (2008). Using Glasow's film as illustrative, Tsakiri contrasts disability arts, culture and aesthetics with mainstream depictions of disabled people as strange curiosities, scroungers and work-shy. Importantly she notes that in such representations, disabled people are often drawn together with working class people, homeless people, immigrants, people of color and other marginalized groups. Tsakiri also furthers our introduction as she discusses the complexities of the gaze and the stare, arguing that documentary films can potentially offer staring encounters guided by disabled people. Drawing on crip killjoys and crip willfulness (Johnson & McRuer, 2014),

Tsakiri argues that *NoBody's Perfect* offers the opportunity to re-examine established canons of aesthetics and negotiate representations of the disabled body.

In *My Infectious Encounters as an Autistic Epidemic*, Jessica Benham also challenges mainstream representation. Here she particularly resists understandings of autism as deficit or separate to personhood, or that disabled people must assimilate or 'pass' as non-disabled in order to be valued. Through her writing, Benham positions herself as/within a global autistic epidemic: a 'repulsively yet beautifully contagious activism' (p. 1). Yet, exploring advocacy within austerity, Benham argues that autistic peer support only partially compensates for a distinct lack of appropriate services. Her mother's words, 'You can be anything you want' resonate throughout - and Benham questions the reality of this utterance under austerity. Benham's explorations also touch upon queerness and madness as identities that intersect, for her, with autism and disability. Drawing on Kafer's (2013) work around queer crip temporalities, Benham makes the case for desiring queerness and disability as always unfinished states. Ending her powerful piece, Benham writes, "When she was young her mother told her she could be anything but she never wanted to be anything else."

Many Disability Studies scholars will be familiar with Lennard Davis' (1995) work on the bell curve. In the final piece, *Reclaiming the Margins in The Face of the Quantified Self*, Gabi Schaffzin (n.d.) furthers Davis' work as he focuses on the power of statistics and data in new and emerging normalizing technologies. Similarly to Benham, Schaffzin also takes an autoethnographic approach as he theorizes his own relationships with the 'quantified self.' Here, however, Schaffzin's approach to ethnography is visual and digital: interpreting, exploring and critiquing data from his own 23andMe and Fitbit accounts. Schaffzin moves us to wonder about the impact of (now relatively mundane) technology which undoubtedly expects and desires particular bodies, minds and selves. Furthermore, Schaffzin highlights the problematic relationships between capitalism and quantified selves: from the political, as our intimate data 'are offered to corporations promising knowledge and freedom' to the practical and everyday; the ways that data is moved between (authorized and unauthorized) companies, for example, and decisions, such as insurance, made on its basis.

Drawing Some Conclusions

To sum up, then, this forum offers an eclectic collection of thought-provoking and engaged articles that contest, challenge, and celebrate our original understandings of crip, fat, ugly and austerity. We extend great thanks to our contributors who have contributed such vibrant offerings. As a collection, the articles expose, critically resist and play with normative understandings of what bodies should do and be. As we have storied our process in this introduction, we have pinpointed some important inclusions and omissions - not only have race, queerness and fatness stayed relatively untouched, but austerity has been a lurking rather than explicit backdrop in the key contributions to this forum. In the current political context of rampant global neoliberalism, it is deeply important we keep pushing back at the always-narrowing boundaries that austerity-as-ideology brings to the body politic. We must keep at the forefront that neoliberal-ableism and global instability inevitably proffer new forms of

precarity that drive us, at best, back into the normative body and self and find creative, collectivist and connected ways to resist. Yet, as per our original call, we want to suggest – as Mingus (2011) does – that a way forward, or at least a place we might begin, is to work together to make space to imagine the Crip, the fat and the ugly as ‘our greatest strength’. We learned across this forum that while we may be ready for the revolutionary politics of Crip and Fat, ugly has got some way to go. It has become clear to us that reclaiming, respecting and loving ugly is an incomplete but, we hope, an emerging radical project that can enable connection and build coalition across marginalized people’s social movements.

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Jen Slater is a Reader in Disability Studies and Education in Sheffield Institute of Education, Sheffield Hallam University, UK. Their research focuses on issues of disability, gender and the body. They are also interested in critical explorations of developmental discourse and issues of access/accessibility. Jen draws on critical disability studies, queer theories and feminisms to explore how relationships between disability, gender, sexuality, race and youth/development function under (neo)liberal agendas of transnational capitalism. Their book, *Youth and Disability: A Challenge to Mr Reasonable* (2015), explores youth and disability as social, cultural and political constructs, alongside gender, sexuality and the body. They are co-editor of *Theorising Normalcy and the Mundane: Precarious Positions* (2016). More recent musings have taken place through a cross-disciplinary, arts-based research project called, *Around the Toilet*, which explores the toilet as an embodied space of exclusion and belonging (www.aroundthetoilet.com). You can read more about Jen’s work at www.jenslater.wordpress.com, or follow them on Twitter @jenslater_

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Endnotes

[i] We follow others in using ‘body-minds’ in order to critique the Western separation of ‘body’ and ‘mind’, and the prioritisation of mind over body. For discussion see Clare (2017, pp. xv–xvii).

Forum - The Crip, the Fat and the Ugly in an Age of Austerity: Resistance, Reclamation, and Affirmation

My Infectious Encounters as an Autistic Epidemic

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Abstract: In contrast to understanding of Autism as an ugly¹ disease requiring a cure, I position myself as autistic *epidemic* - a repulsively yet beautifully contagious activism and blend my story through a crip'd, queer'd temporality². Intentionally opaque, I resist a naive economism that disabled bodies must perform normatively, legible labor to be valued. In this age of austerity, autistic peer supports can only partially compensate for the lack of available, affordable services.

Keywords: autism, epidemic, gender

Accessibility Note: Throughout this piece, a variety of font styles and colors are used to convey meaning. At times, labels like “girl” or the first letter of “Autistic” appear in scarlet. Bold emphasizes some words, while italics inspire us to reflect back. Words that are fun to say, like *stimming*, are sometimes extended. Some words are in larger font than others and more quickly draw our attention. At one point a page is left intentionally blank. At other points, a sloppy font, called ‘chalkduster,’ is used; it looks like the scrawl of someone just learning to write. Another font, Copperplate Gothic, appears stark and in all capital letters. Open Dyslexic is curvy, intended to be easily legible. Some parts are underlined, reminiscent of paging through a well-loved book.

“BY GROUNDING AUSTERITY IN
LIVED EXPERIENCE. WE ARE ABLE TO
GRASP THE COMPLEXITIES AND
CONTRADICTIONS THAT ARE
CENTRAL TO AUSTERITY’S LIVED
MANIFESTATIONS”

(Hitchen, 2016, p. 102).

When I was young, “**Repulsiveness**” “The contemporary perception of autism

Calamity, my mother told me, centres on an idea of trauma

I could be anything I wanted. scourge, the ‘epidemic’ of new diagnoses that blights...

But I never wanted to be anything else. the ‘tragedy’ of the child ‘lost’ to the condition.”

and evilness” (Garcia, 2010, p. 56) (Murray, 2008, p. 94).

Garcia (2010) argues that **ILLNESS** metaphor powerfully persuades.

“TIMES OF AUSTERITY ARE, ALSO,
TIMES OF CONTRADICTION.”

(Veck, 2014, p. 777).

No diagnosis, *she* hates labels. But *it’s a* **girl.**

Ask a femme her gender *meh*

lazy,

why bother

Autistic cares not, but ~~constrained~~ restrained

“AUSTERITY IS A *MULTIPLICITY* THAT
SURFACES IN NUMEROUS DOMAINS
OF PEOPLES’ DAY-TO-DAY
PRACTICES. EVERYDAY LIFE
MATTERS, AS AUSTERITY IN THIS
CONTEXT IS SOMETHING THAT IS

EXPERIENCED BY LIVING BEINGS,
AND THEREFORE IS UNDERSTOOD
THROUGH INDIVIDUALS' LIVED AND
FELT REALITIES”

(Hitchen, 2016, p. 103).

The symphony of empty redbull cans

As we accelerate and brake

Symptomatic, my medication

Caffeine

Excite, awake,

A*utistic* *is here on the bus this*

morning

Illness, *Catching the bus at 6 AM,*

evil, *car headlights wink at me as they bump*

rhetorically powerful,

Over the dip

politics makes it so *Car headlights caught stimm*

mmm **Says Sontag (1989)**

mmm

mming from me.

The sparkling city my backdrop

**“Austerity is also something that is expressed *affectively*, as it is felt by individuals through affective intensities”
(Hitchen, 2016, p. 103).**

I

“Austerity may

Go

be expressed through

To my office

bodily affects of fear or anxiety

Trap the ideas in paper prisons

even feelings of hope” (Hitchen, 2016, p. 103).

Infect new department

“To create inclusive schools,

Autistic *is here in the office this morning*

Gilbert-Walsh (2007) writes, “There are those who claim that the narrative interruption characteristic of deconstruction

what is required is a shift from a culture of mass
indifference, fuelled
by

Don't touch, you might catch it

is not a silent negation of narrative; but is rather one narrative voice breaking in upon another” (p. 322).

Too many grad students share this space

mass

competition,

“The effects of such media portrayals of autism need to be understood. It is not quite the kind of ‘hysterical epidemic’ that Elaine Showalter discusses in her 1997 study Hystories, but the notion of a ‘hysterical hot zone,’ as Showalter terms it, or the spread of an epidemic through stories, and an idea of contagion, seems relevant and germane. Autism is physical and neurological in a way hysteria is not.” (Murray, 2008, p. 28).

to a culture of attentive care.

Certainly, imposter syndrome catching

inclusion and

exclusion,

Why not my infectious thoughts?

might be witnessed

as having real consequences

Munro and Belova (2008) call into existence: “Moments that take the form of breaks in narrative,

wherein bodies unexpectedly find their comportment to be out of line” (p. 87).

for individuals who are not simply

like me

Ally...is

but are persons to whom I am

responsible

Ally...is

with a responsibility that is the

source of

Ally...is

my becoming” (Veck, 2014, p.792).

Ally...is Someone who feels good about themselves when they speak for me.

I was at the Warhol Museum in Pittsburgh, advising on a series of sensory-friendly events for teens and adults.

Ally...is Able-minded people who “understand” what I’m going through.

An Autism mommy, you know the type, was talking about the importance of the programming,

Ally...is “Friends” who like me “despite” my autism.

“You know, it’s like an epidemic, this autism, so many more of them around. But we really have to talk about them as people first, that’s what they want.”

Ally...is Professors who, in the interests of “protecting” me, tell me I need to “adapt” (read: pass) more to make it in grad school.

“current approaches to the education and care of disabled people,

My hand raises quickly, seemingly of its own accord,

“No, it’s not. I am not contagious, my

autism is not something you can catch.

along with present policies of austerity,

AUTISTIC is in the Warhol

can be understood only in relation to the decline of both actual
community

Ally...iS Research funding for a cure I don't want.

and the concrete hope for its existence" (Veck, 2014, p. 778).

Autistic is just an adjective, just a word. If you need to be reminded that I'm human,

Ally...iS Advocating therapy when I seek life skills.

"the bulk of the support for metaphorically framing autism within a disease model comes from within the non-autistic ('neurotypical' or 'NT') community, whereas the bulk of the support for metaphorically framing autism within a neurodiversity model comes from within the autistic community (and is inclusive of some non-autistic allies as well)" (Broderick & Ne'eman, p. 459)

that I'm a person first,

Person first.

Person first language.

then maybe that says more

about you than about me."

Ally...iS Rarely actually on my side.

Like an epidemic, the shock spread...yes, this mild-mannered brunette rocking in the corner has a voice and

Ally...iS Not. Listening.

even if I didn't speak in ways *Langellier (1999) emphasized the importance of sharing personal narratives*
you wanted me too,

,arguing that it "situates us not only among marginalized and muted experiences but

I would still always be communicating. *also among the mundane communication practices of ordinary people.*" (p. 126).

“The moments
in which
austerity
surfaced were
seen as a
disruption to,

rather than part
of, everyday
rhythms”
(Hitchen, 2016,
p. 117)

*“a perplexity in the face of
narrative, When my autism infects you, a perplexity*

in the face of a story, let it help you see the world the
 way I see it. *about narrative that we*
have always already begun Full of bright
 colors that make loud crashes in my head, full of a joyful pain. *but are*
never able to finish Let the infection of my autism help you
 understand why eye contact hurts so badly. .”[Gilbert-Walsh,
 2007, p. 329] Let the contagion bring you into my world instead of you
 forcing me into yours. *Semino, Deignan, and Littlemore (2013) linked vaccine and epidemic to*
ILLNESS metaphor.

Munro and Belova (2008) note that there are “ways in which bodies can

be said to absent themselves When I was working on my masters’ thesis

by getting ‘in line’ with I could not balance being autistic

social and and being in school. “*Compulsory heterosexuality is intertwined with compulsory able-bodiedness; both systems work to (re)produce the able body and heterosexuality*” (McRuer, 2006, p. 31).

organizational narratives” (Munro & Belova, 2008, p. 90).

“A queer/disabled existence that can never quite be contained” (McRuer, 2006, p. 31).

Autistic is here in the psych ward this morning. *“Able-bodied heterosexuality’s hegemony is always in danger of collapse” (McRuer, 2006, p. 31).*

“in a contemporary world of vaccine scares...They never turn out the

lights....*differences of medical opinion....*

in this psych ward. I can turn off the **lights** in my room, but the

hallway*discussion of an autism ‘epidemic’...*

lights glow through the gClass walls. It’s impossible to

sleep in a zoo.

...the condition occupies contested found in an arena in which it appears as it little is agreed upon” (Murray, 2008, p. 6)

The lovely thing about Mayo Clinic is that patients have access to all written reports about them.

Here, I interrupt

She reports that

Reclaim

I am anxious, not suicidal

she has had some symptoms of

crip

depression anxiety

queer

for the past few months,

what was said about me

but thought she was managing it well conservatively on her own

I am scared but not of life.

and then in the past 2 weeks things have just gotten worse.

I am scared of the shaking,

She is having panic attacks daily,

the pounding,

mostly in the morning and evening.

“The desirability of a loss of composure” (McRuer, 2006, p. 149).

the quickness of breath,

When she goes to work she will have them only about every 3 hours in which her mind races. **“It is only in such a state that heteronormativity might be questioned or resisted and that new (queer/disabled) identities and communities might be imagined” (McRuer, 2006, p. 149).** *“Not only might they cause time to slow, or to be experienced in quick bursts...”*

She gets very worried and has difficulty catching her breath.

the way the world seems to spin around me

She has increased stress from school.

...they can lead to feelings of asynchrony or temporal dissonance... “Desiring queerness/disability ...depression and mania... means not assuming in advance ...are often experienced through time shifts...” (Kafer, 2013, p. 34) that the finished state is one worth striving for,

especially the finished state demanded by the corporate university” (McRuer, 2006, p. 159).

Diagnoses

“IN THIS ERA OF AUSTERITY IT IS IMPORTANT THAT

DIAGNOSIS IS COST-EFFECTIVE BUT REMAINS OF A HIGH QUALITY AND

FAMILY CENTERED” (KARIM, COOK, & O'REILY, 2012, p. 116).

1.) Major depressive disorder, recurrent, severe.

“Amid concern about a so-called autism epidemic,

2.) Panic disorder without agoraphobia. stereotypes abound.

3.) Autism spectrum disorder *“the idea that curing or preventing*

autism is priority number one in autism research” (Gross, 2012, p. 268)

“IN THESE TIMES OF AUSTERITY IT IS IMPERATIVE THAT THE DIAGNOSIS

OF ASD IS MADE IN AN EFFICIENT MANNER CONSIDERING

THE SUBSTANTIAL RESOURCE REQUIRED” (KARIM ET AL., 2012, p. 120).

with features of obsessive compulsive disorder

“Autism is indeed an unalterable condition, and many people have spoken about it metaphorically in ways that...construct autism as death, or a fate worse than death, for an otherwise-normal child” (Gross, 2012, p. 263).

4) Phase of life

problems

People on the spectrum are metaphorically represented as machines, aliens, or computers. (Loftis, 2015, p. 4)

“Autism becomes an almost mystical force...I would never end my life ...

a sort of bad luck charm which attracts death (Gross, 2012, p. 264).

over an anxiety attack, just please, please give me my meds

“queer kids, kids of color, street kids - all of the kids cast out of reproductive futurism...

And stop bothering me. ...have been and continue to be...

I know you have to check every 15 minutes ...*framed as sick*

But how is one supposed *as pathological* to become healthy *as contagious” (Kafer, 2013, p. 32)*

in a zoo?

“Portraying us as non-entities - corpses, empty shells - or as being without agency, awaiting rescue” (Gross, 2012, p. 269).

I want a bath now,

Don't put me in the box of your preconceived notions

“Autists³, then, draw attention to what the philosopher Michel Serres has called ‘the hardness of language’ - its sound waves, acoustical texture, density on the page, and so forth.

but they want me to go to another one of those stupid meetings.

Boxes are for boring people who don't know how to

Dream in a different language

To the extent that they value words from a sensate perspective, autists partially remove language from the

‘soft’ realm of data processing

Since they are taking away my choice on the bath,

I have chosen

Doesn't translate to your verbal backlash

To my stimming presence

placing it into ‘the hard scale of entropy, music, rhythms, cries and noise, sun or lightbulb’ (116-17)”
(Silverman, 2016, p. 312)

not to go to their meeting.

Limited perception makes my words lack meaning

Those meetings make me more

anxious.

Hear my entire meaningful beautiful stimtastic transmission

Hell, being here makes me

Just because I can pass as NT doesn't mean I must

anxious.

Make you feel comfortable

“Some parents and doctors, convinced that

You are already comfortable dismissing me

autism is separable from the personhood of autistics,

Blaze a Scarlet  across my chest

“Letters become important for their physical substantiality as well as for the satisfactors they generate in those who engage them” (Silverman, 2016, p. 312).

But I, I will hold that burning sensation in my mouth
will do terrible things to

Spend my entire life feeling lesser
“get the autism out”

Since my neurology is not in vogue
of their children or patients.” (Gross, p. 266)

My autism won’t go into remission
Stop Combating Me.

“To recognize that autism diverges from this narrative is to affirm unorthodox linguistic approaches and to concede their ability to complement normative practices” (Silverman, 2016, p. 313).

When she was young

“In an age of austerity, however, when jobs remain hard to find in most parts

I am not a girl.

of the country, the reduction in disability numbers and spending looks set to

Her mother told her

be achieved not by moving claimants back into work but by diverting them

I am not a WOMAN.

between different parts of the benefits system or, in many cases, out of the

She could be anything she wanted

benefits system altogether. This is hardly a lasting or satisfactory solution to

Already always in transition, transaction.

the underlying **problem.” (Beatty & Fothergill, 2015, p. 179).**

too gender-lazy to move.

There is no cure for my infection and you cannot not inoculate yourself Against me. *“This behavior extends to Sometimes I pass invisible near you. autists’ intercourse with language; What you don’t know can’t hurt you, they say. But my perspective is still catching. a rich experiential relation to words and letters*

Sometimes I reveal myself, the source of the infection, - LOUDLY - to you and what you do know somehow doesn’t hurt you, only me. *often in excess of meaning” (Silverman, 2016, p. 308).* Others, immune to patienthood, easily remove their emotions from discussions of ethics, discussions of autism; never having been *patient*, it is easy to discuss. *“An intense intimacy and intercorporeity I am never, not patient. with words and letters I am never, not patient with them. with vibrational sounds of reading aloud” (Silverman, 2016, p. 309)* I am always, often called to patiently educate, never equal.

AUTISTIC is in the seminar room. Sometimes I say I have had enough because no matter how often we say we are talking about other people, we are always talking about me. *“When letters and books become objects of bodily correspondence and identification, And they say, in a form letter required to send to all students, “The faculty are especially impressed with the depth of insight that you contribute to discussion and your articulation of perspectives too often omitted from bioethics perspectives.” they emerge as the equals of the subjects who engage them” (Silverman, 2016, p. 309).* **AUTISTIC is at the colloquium.** And I wonder, if they really mean it. The neurotypicals always say, actions speak louder than words. **“Affective responses to material words...Perhaps, my presence, the epidemic of my words ...mix with intimations of meaning to produce...which refuse to stay contained within**

my mouth,...a richer, more capacious... spewing out like a sneeze, ...encounter with language. are only appreciated insofar as I remain, happily, patient zero, happily, zoo exhibit. How is one to learn in a zoo? **The autistic here is bimodal, mining language for its meaning and its materiality and, in the process expanding traditional epistemological frameworks**" (Silverman, 2016, p. 313).

Autistic is at a meeting of advocates discussing new services to be provided in Pennsylvania.

“progressive localism – a term used

to convey the emerging organic forms of local politics in the wake of austerity

Autistic is told what she, and everyone else “like” her, wants. **Autistic** is spoken over until she shouts, in response to being told that “everyone wants friends,” I DON’T WANT ANY FUCKING FRIENDS. **“Finding resonance with inanimate matter... Someone’s glass clinks, ...entails devaluing human status...everyone’s eyes burn toward mine. ...engaging on equal terms with one’s environment”** (Silverman, 2016, p. 317).

most localism

policy assumes the role of dynamic, well-resourced communities (alongside private sector firms)

and fails to recognize the radical plurality of many localities”

(Power, Bartlett, & Hall, 2016, p. 185).

Autistic is heard and you, you could not remain uninfected. Autistic tried so hard to be professional, but contagion cannot be contained.

*When she was young
Her mother told her*

She could be anything
But she never wanted to be
*A*nything else

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Endnotes

1. Ugly, like the “Ugly Laws” which prohibited people with disabilities deemed unsightly from appearing in public in major cities in the United States, many of which were not repealed until the late 1970s. See (italic title) *The Ugly Laws: Disability in Public*, by Susan M. Schweik for comprehensive discussion.
2. Here I reference Alison Kafer’s *Feminist Queer Crip*, particularly her theoretical perspective on crip temporalities as different from normative time. I have also been inspired by the styles of Derrida and Ronell, as well as Spry’s (2001) understanding of auto-ethnography as moving between “being there” and “being here.”
3. “Autists” is sometimes used as a noun-form of autistic by people who strongly believe that autism is identity.

Forum - The Crip, the Fat and the Ugly in an Age of Austerity: Resistance, Reclamation, and Affirmation

Reclaiming the Margins in the Face of the Quantified Self

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Abstract: Through the lens of my own experiences with a chronic and painful condition, I consider the ways that quantified self devices and services normalize and classify, creating a new kind of relationship to our medicalized conditions. My project seeks to co-opt these technologies in the service of revealing proprietary and arbitrary translations relied on to make decisions using QS devices.

Keywords: quantified self, art practice, ethnography

Introduction

My diagnosis came from a doctor at Massachusetts General Hospital in August, 2010. She asked about my family and my love life, pinched my skin and prodded my scars, took copious notes, and then wrote up a thorough report with her verdict: Ehlers-Danlos Syndrome, a genetic collagen deficiency. The diagnosis was no real surprise—my sister, 12 years my elder, was diagnosed by the same doctor a year or so earlier. Her EDS had progressed beyond my condition at the time—her chronic joint pain, “stretchy” skin, and immunodeficiency were much more pronounced and took a more significant toll on her daily life. Our doctor, however, could not be more pleased with her recent findings: as a geneticist, having siblings present with similar symptoms at varying stages of severity was a goldmine of study fodder.

Until August 2010, Ehlers-Danlos looked like this: day-long (or more) pain after particularly strenuous exercise, scars that look like cigarette paper, “showing off” veins that bulge despite my non-muscular stature, skin that stretches further off my muscles than most, and limbs that bend awkwardly. A few weeks after my 18th birthday, my lung collapsed spontaneously. Later that year, I was diagnosed with Ulcerative Colitis, the kind of gastro-intestinally-based immunodeficiency often associated with EDS. For the years before and nearly a decade after, I simply considered myself an unlucky but relatively typical Ashkenazi Jew (I was often told that, “yeah, this sort of thing is common in white skinny Jewish boys”). But now there was a name for all of this, a doctor’s report, and an entry on the online medical reference, WebMD.

Efforts to quantify the body and self through the use of personal devices and services—efforts which are increasingly considered valid and valuable in medicine—are creating a new kind of relationship between ourselves and our medicalized conditions, one that leads to an exploitation of the self by corporate and regulatory bodies alike. I seek here to elucidate these exploitations through an autoethnographic pursuit that reveals the proprietary and arbitrary nature of the translations one relies on to make decisions in one’s life using

quantified self devices. I use resources at my disposal as an artist, technologist, and scholar to consider questions of the hegemony of measurement and language, what it means to be in pain, and—most importantly—how one might reclaim our body from what I will demonstrate as a strongly neoliberal conceptualization of the self.

What follows is an exploration of my disease as seen through two self-health products built upon systems which collect and interpret data about the individual using them: 23andMe and the Fitbit Flex wristband. The project is informed by methodologies of visual and digital ethnography. The former, as outlined by Sarah Pink (2001), includes “the use of visual images in research and representation” (p. 31). And while the latter, per Pink et al. can incorporate the same methodologies as the former, it is complicated by the fact that digital technologies allow the ethnographer opportunities for mediation as well as observation (2015, p. 3). My project is further complicated by the fact that what is being looked at is not in itself visual representation, but a breaking-down of the technology used for that representation alongside a context of how that technology is designed, developed, and sold. As such, I utilize both code studies—wherein computer code is considered a “mechanical device for the production and consumption of verbal signs” (Aarseth, 1997, p. 21)—and material culture studies, understood by Pink et al. as based on an argument. The argument is:

“That objects and things, the materials used to construct them and the properties of these materials are central to understanding culture and social relations: humans play as much of a role in the creation of objects as objects create the conditions of human life” (2015, p. 61).

All of this is being done in the service of subverting the biopolitical hegemony exercised by an assemblage of actors developing, designing, and selling products that purport to help me find the “one unique [me]” (“23andMe”, n.d.-b) or to “find [my] fit” (“Why Fitbit”, n.d.). At the outset, then, it is important to establish an understanding of what element of “me” I seek to explore.

Per Parapia and Jackson, individuals with (the yet-to-be-named) Ehlers-Danlos Syndrome were identified as far back as 400 BCE, when Hippocrates described a specific type of bleeding and bruising in his subjects (2008, p. 32). Twenty-five hundred years later, Edvard Ehlers (1901) and Henri-Alexandre Danlos (1908) began to connect formally the diagnosis of the condition to its symptoms: “lax joints, hyper-extensible skin and a tendency to bruising” (Parapia & Jackson, 2008, p. 32) and other various connective-tissue anomalies—all conditions that can be observed by a close physical exam (as opposed to being identified via, for instance, a blood test). Even after the genetic markers for EDS were recognized in the 1960s, EDS is still a disease diagnosed through observation and touch (“What is Ehlers-Danlos”, n.d.).

If the disease is, in fact, hereditary, it follows that “seeing” one’s genetic variants would reveal the presence of Ehlers-Danlos in oneself. This, then, is where my project begins: seeing the disease. What ethnographic methods are available to observe the presence of EDS in a subject? As the MGH doctor already demonstrated, poking, prodding, and

interviewing are clinically sound approaches. But how might I discover, document, and understand a condition which is only barely perceptible to the trained eye? Corporations selling so called “qualified-self” devices or personal genomic services offer that their products will reveal insights not otherwise knowable or visible without the use their wares.

An Introduction to 23andMe

When I was diagnosed in 2010, Silicon Valley based 23andMe had already been collecting and genotyping human genetic samples for three years—though they were doing so at the prohibitively expensive price of \$999 (Herper, 2011, para. 1). The company, which has received hundreds of millions of dollars in private investment (“23andMe”, n.d.-a), collects saliva samples from its customers via the mail and uses those samples to genotype each customer’s DNA. For some time, the resulting charts and graphs would include probabilities of being diagnosed with certain diseases (cancer, diabetes, et al.), chances of going bald, certain genetically determined physical traits, and other various facts (ancestry data, for instance) (Murphy, 2013). In late 2013, the U.S. Food and Drug Administration filed an injunction that prohibited the company from making disease-related predictions, though 23andMe and the FDA eventually agreed that reports could include carrier status and ancestry data (Ouellette, 2015). Under the Trump administration, the FDA loosened its regulations on how the company markets its “Health + Ancestry” kits, which, in late 2017, cost \$199 (you can purchase an “Ancestry Only” kit for \$49) (Keshavan, 2017). The kits act as a loss leader—the company believes that building as large a database as possible of genomic data will lead to profitability. Indeed, in early 2015, the biopharmaceutical giant, Genentech, paid \$60 million for access to the genetic data of those “spitters” who opted-in to have their genome shared (at the time of the deal, that was 600,000 of 800,000 customers) (Herper, 2015; Ouellette, 2015).

In each human, one cell’s nucleus contains a three billion unit string of genetic data. Each unit on the string is a nucleobase represented by an A (adenine), C (cytosine), G (guanine), or T (thymine). Of those three billion or so bases, only ten million vary between individual humans; that is, 99.67% of our genetic data is identical to every other human. The ten million bases that vary, or single nucleotide polymorphisms, contain our genotype: the DNA data that affects how one looks or what diseases manifest in one’s body and so on. In an evolutionary biological sense, our genotype is what makes us “different” from one another. As of 2015, 23andMe’s technology revealed the genotype of just over 600,000 SNPs (“Genotyping technology”, 2015).

My Experience with 23andMe

Understanding the technical details of 23andMe’s offering is critical to my project, especially as I consider the marketing rhetoric surrounding the product. On the 23andMe homepage for prospective customers (as opposed to those who have already spit), one learns that the company is “an experience that lets [customers] explore [their] genetics throughout [their lives]” and that “it’s just saliva” that makes the service work. The company promises to

reveal the “one unique you” (“23andMe”, n.d.-b). On the “spitter”-facing site, those of us who have sent our DNA to the company (I did so in the summer of 2014) are presented with the lab-chic aesthetic of biomedical information design: simple in form and color, the work includes an integration of iconography with an emphasis on the graphical, rather than the textual, to convey a communicative goal, be it empirical observation, narrative, or instruction.¹ Pie graphs tell us the probability that I have dark hair or how likely it is that I consume more caffeine than the average 23andMe customer; ancestry maps connect me back to Neanderthals (via <http://you.23andMe.com/> with a username and password).

Reviewing 23andMe’s marketing-speak alongside the technology behind its service highlights two poles on a spectrum: the colorful (literally) excitement of our results acting as the interface to the banality of saliva on a microchip. The data underlying the company’s inspirational rhetoric and seductive data visualizations can be described using Mathew Fuller and Andrew Goffey’s (2012) “grayness,” a concept they adapt from Primo Levi’s description of ambiguous internal politics in Nazi Lagers into a way to frame functionally banal technology. In their 2012 *Evil Media*, they write of grayness as, “A quality that is easily overlooked, and that is what gives it its great attraction, an unremarkableness that can be of inestimable value in background operations” (p. 11). The 23andMe designers, then, have taken the unremarkableness of one’s genetic data and dressed it in the excitement of an early-21st century biomedical startup.

Downloading and opening my 23andMe “raw data” file, I find 610,546 lines of text. On each line is tab-delimited data: an rsid (unique SNP identifiers), a chromosome label (1 thru 23, X, Y), a number representing the position of each SNP on my chromosome, and its genotype (a usually two-letter combination of A, G, T, and C). Considering my relatively new classification as an individual with a genetic deficiency, my immediate instinct is to seek out proof of my Ehlers-Danlosian status. I choose one of a handful of online genotype references, snpedia.com, and search for Ehlers-Danlos. The resulting page (“Ehlers-Danlos syndrome”, 2016) tells me that “EDS is caused by a defect in the structure, production, or processing of collagen or proteins that interact with collagen, such as mutations in the COL5A or COL3A genes” (para. 1). 23andMe allows you to search your data by gene through their online “raw data” interface, so I do this. Too many SNPs are listed to go through each one and find where my EDS is; the hints I do find seem too enigmatic to a non-geneticist such as myself.

Delving into their “gray media” concept, Fuller and Goffey are sure to point out that grayness does not indicate media which bears “some sort of hidden meaning that might be brought to light...but a certain recessiveness is often a crucial aspect of their efficacy” (2012, p. 12). The authors highlight this recessiveness as critical to their study and I will do the same here. Gray media is obfuscating: the rows and rows of text—be they genetic data, encrypted hex values (as I will demonstrate below), or the lines of code which generate these corpora—are not meant to be read by humans. They are banal in their obtuseness, lulling the brain that tries to read them into giving up. These are, to be sure, defense mechanisms; like the cephalopod’s chromatic camouflage, gray media stays unread as long as it is unreadable.

The Quantified Self

Keeping raw data and proprietary algorithms hidden as often as possible is key to protecting the intellectual property and “value-add” provided by corporations which sell products and services relating to the “quantified self”, or QS, movement.² The quantified self refers to the use of technology to track someone’s activity, health, or other personal metrics in order to improve upon quality of life. With roots in self-experimentation and self-science, the QS movement as understood today is built upon miniaturized electronic sensors—motion, temperature, and so on—embedded in consumer devices. This miniaturization requirement is critical to understanding why the market for these devices has grown exponentially in the past decade, especially alongside the development of high-density, cheap, and fast connected-storage technologies (often referred to colloquially as “the cloud”). When a device can log every minute movement, those data are relatively useless if they cannot be calculated and stored centrally. The same can be said for logging and interpreting 600,000 genotypes for over one million “spitters”.³

Until 2016, the majority of writing on QS was short-form—primarily works espousing the possibilities that the use of self-tracking devices and services brought to the fore. At the CHI 2014 conference, a group from the University of Washington, along with a number of researchers at Microsoft Corporation, produced “a qualitative and quantitative analysis of 52 video recordings of Quantified Self Meetup talks to understand what [participants] did, how they did it, and what they learned” (Choe, Lee, Lee, Pratt, & Kientz, 2014, p. 1143). Self-proclaimed “Technology Futurist and Academic Researcher” Melanie Swan published a number of papers between 2009 and 2015 which offer ways that the use of quantified self devices will “disrupt” (2013) or “crowdsource” (2012a; 2012b) health data. Professor in Communication at the University of Canberra in Australia, Deborah Lupton, has been similarly prolific, bringing a more academically-minded and sociological approach to researching the movement (2013; 2014; 2015).

By the end of 2016, however, a number of long-form scholarly works were published, each providing a range of theoretical and ethnographic explorations into QS. This collection includes *Self-Tracking* (2016) by a pair of American researchers, Gina Neff and Dawn Nafus, and *The Quantified Self: A Sociology of Self Tracking* (2016) by Lupton. These came on the heels of the Nafus-edited *Quantified: Biosensing Technologies in Everyday Life* (2016), an anthology of essays on self-tracking through varied lenses such as the social sciences, journalism, industry, and cultural studies. While these works are not necessarily historical in nature, they do note a relatively recent shift in a focus from “n of 1” studies—that is, tracking one’s own data for the purpose of one’s own improvement—into a more collective approach (measuring an individual’s data against an entire customer base, for instance). Lupton (2016) writes of a move to the “quantified us”, quoting a 2014 blog post by design consultants Matthew Jordan and Nikki Pfarr: “One of the ways...to have more impact [with QS], is to bridge the gap between Big [sic] and small data, and to heighten the collective relevance of the data we track about ourselves” (as cited in Lupton, 2016, p. 131).

The economics of scale provided by corporate QS systems and products, then, help make the data generated “valuable”: albeit paradoxically, the quantified *self* depends on the actions of many *others* for “proper” scientific gains. In his 1981 article, “Self-Experimentation: A Call for Change,” Allen Neuringer writes that in self-science, “as in science generally, progress depends upon the interaction between individual experimenters: to generate background information and hypotheses, to check results, to provide missing pieces for the puzzle” (p. 92). Thus, even though the quantified self movement was, for all intents and purposes, launched as just that—a movement—rather than “an industry”, as Choe et al. note, barriers to finding value in the practices therein include the time, tools, and skills necessary to collect and analyze the data (p. 1143). These are all problems which corporate financing and market-based strategies can address.

Of course, there are problematics associated with the QS movement before or after the aforementioned barriers are overcome. It is not difficult to imagine some of these issues, especially in the case of 23andMe: a misinterpretation by corporate or consumer party, leading to taking drastic action (e.g., mastectomy in a perceived high-cancer-risk individual); an unauthorized third-party gaining access to one’s DNA; or an *authorized* third-party using the data for surveillant⁴ or nefarious purposes (denying insurance to a child due to her parent’s carrier status). However, while these dystopian scenarios are certainly troubling, it is more productive to consider the greater power at work here.

In his essay, “How Should We Do the History of Statistics?”, Ian Hacking (1991) highlights the bureaucratic power of statistics by referencing Michel Foucault’s bio-power, or the state’s control and discipline over the body:

“One need not subscribe fully to this model [i.e., bio-power] to see that statistics of populations and of deviancy form an integral part of the industrial state. Such a politics is directly involved in capital formation through social assurance...” (p. 183).

Continuing on this theme, Hacking uses Marx’s utilization of statistics in his own work when pointing out how statistical bureaucracy had changed the state: “It is a glib but true generalization that proletarian revolutions have never occurred in any state whose assurantial⁵ technology was working properly” (p. 184). Hacking’s piece was written around the same time as the publication of his larger work, *The Taming of Chance* (1990), which provides a more thorough investigation into the erosion of determinism and emergence of statistical powers of the state. But his essay is a good starting point from which to begin to consider the hegemony of statistics and how the grayness of large bodies of data may not only obfuscate to protect, but also to project an aura of truth. That is, if the file I download from 23andMe is too large to parse through myself, then the data within must be valid. As Chris Anderson offers, albeit facetiously, in a 2008 article in *Wired*, “With enough data, the numbers speak for themselves” (para. 7).

Another paradox presents itself: in QS-inspired “dashboards”—webpages with an overview of one’s collected data, abstracted and interpreted to be most relevant to one’s goals and motives—one finds the aforementioned seductive data visualizations. These graphs and

charts are, purportedly, based on the troves of data sitting in a company's database. The visual properties of the graphics, however, provide users with an abstraction that both makes the data more relatable and comprehensible than rows of numbers in a spreadsheet or database (see Neff & Nafus, 2016, p. 82; Kennedy & Hill, 2017, p. 2).

We are, then, at once seduced by the reductively simple and the overwhelmingly complex. And within this paradox sits our condition: our carrier status, our daily activity levels, our pulse, blood pressure, or weight. But who are the individuals who decide what to collect, how to interpret it, and in what form to display it? I wish to liken these individuals—product designers, developers, marketers, investors, and so on—to Elaine Scarry's "torturers" as they turn a feeling or condition into something seen or heard, make it real, and take advantage of its apparent state. In her 1985 *The Body in Pain*, she writes:

"If the felt-attributes of pain are (through one means of verbal objectification or another) lifted into the visible world, and if the referent for these now objectified attributes is understood to be the human body, then the sentient fact of the person's suffering will become knowable to the second person" (1985, p. 13).

These torturers translate the intangible into the tangible, forcing its reconstruction in a purely visible form, giving us reason to doubt when a visualization may not adequately represent, to treat when a threshold is misplaced. Hacking (1990) shares a similar sentiment:

"The erosion of determinism and the taming of chance by statistics does not introduce a new liberty. The argument that indeterminism creates a place for free will is a hollow mockery. The bureaucracy of statistics imposes not just by creating administrative rulings but by determining classifications within which people must think of themselves and of the actions that are open to them" (p. 194).

Once the bureaucracy of statistics is imposed, its subjects are objectified and normalized. They are stripped of agency and noted as a record in a database with millions of others.

My Process & Output

I return, then, to my search for proof of EDS within my 23andMe data. If I understand the larger implications of how power acts on me as a subject of 23andMe, why consent to having my DNA genotyped? Partly, I opted to send my saliva off to Northern California as research because I knew I could not critique a service from which I abstained. More importantly—and more difficult to admit—is that I harbored enough curiosity to submit (perhaps my two reasons are not that different from one another). Scarry (1985), once again, spoke to me: "To have pain is to have certainty," she writes, "To hear about pain is to have doubt" (p. 7). After years of feeling as though there was something "different" about my body, I could finally "prove" it.

There was not much proof to be had—not, at least, in my 23andMe raw data file. The abstracted graphics on the 23andMe site proved even further from valuable: I *did* learn that I have the muscles of a sprinter (as opposed to a long-distance runner) without any warning of

the long-term damage that said sprinting might do to my joints and tendons. I decided that, if 23andMe's version of the quantified self wouldn't indicate something critical which I already knew about myself, then perhaps I could express *myself* using my quantified self.

Neff and Nafus (2016) reference projects that “Satisfy aesthetic curiosity” (p. 80)—projects made by artists using data from their quantified-selves. These projects include Laurie Frick's “Frick Bits” (2014–2017) which use GPS data to create abstract patterns, as well as Stephen Cartwright's (1996–1997, 1999–ongoing) sculptural representations of his latitude, longitude, and elevation data. As Smith and Vonthehoff (2015) explain, some users of quantified self devices wish to go beyond the “self-knowledge” promised and instead construct narratives that can be shared in public space via the commonality of data (p. 12). I, however, was more interested in how I might be able to translate the data in a manner that would highlight its arbitrary and proprietary nature.

Putting 23andMe on hold for a bit, I began considering all of the devices and services available on the consumer market that would allow me to collect raw data. At the top of this list was the Fitbit—a wrist-worn motion tracker whose primary measure, “steps”, has become a standard metric for most entry-level QS devices. If I sought out the *existence* of my Ehlers-Danlos Syndrome in my genetic data, certainly a device that measures my movement would help me “see” the *reasons* for my pain; my joints and muscles are loose and relatively slow to recover from trauma, often the loci of significant pain. Delving into my Fitbit data, then, made a great deal of sense. Secondly, Fitbit data is semiotically further from its referent than a service like 23andMe. Whereas genetic data represents a relatively widely accepted nomenclature (that is, the A, C, T, and G that makes up DNA), Fitbit “steps” are mostly engineered by the Fitbit Corporation. As such, I proposed, the data collected here would not be necessarily readable in the same way that 23andMe raw data was.

I was correct. Per the Fitbit website (though only in the Fitbit customer support section), the base Fitbit model (at the time of my initiating this project, this was the “Flex”) uses one accelerometer—a silicon chip that can sense movement—which measures on three axes (“How does my Fitbit”, n.d.). As the device is moved, Fitbit's software determines if a step has been taken. It then extrapolates the number of calories expended and distance traveled. This data is sent via Bluetooth, a wireless technology, to a smartphone or computer in an encrypted format using hex data—individual base-16 values equating to 0 through 255.⁶ Software on the smartphone or computer then uploads this data to the Fitbit corporate servers, which are loaded with software to decode these hex values and store step, calorie, and distance data.

After wearing the Fitbit for a number of days, I began using software on my computer to intercept the raw data being communicated between the device and software on my laptop via Bluetooth. What I saw was a long list of base-16 values. These values, however, were not raw step data, *per se*. Instead, they were messages being sent in *encrypted* hex values—numbers being transmitted after being scrambled, only properly unscrambled via possession of a secret software-based key that exists on the Fitbit servers. After data was

transferred from my wrist to my laptop, it was uploaded to those servers to be interpreted and added via database records. I could go to Fitbit.com and download a spreadsheet with the interpreted values (steps taken, minutes of sleep, minutes of strenuous walking, etc.), but nowhere could I procure the actual motion data collected by the accelerometers in the wristband.

In fact, this was exactly the scenario I was hoping for. By intercepting encrypted hex values, my step data lost all context. By definition, as digital data, the hex represented a set of numerical values which, in turn, could be used by any other program on any computer as long as that program was instructed to interpret data in the format I fed it.⁷ For example, a basic computer image is made up of an array of pixels, each with three values—red, green, and blue—that range from 0 to 255. This system allows for millions of “RGB” combinations. Placing millions of those RGB combinations into a grid results in an image. In order to turn the step data into an array of pixels to form an image, I simply needed to arrange my Fitbit data in a specific pattern to convince my computer that it made up an image file. After one month of wearing and downloading data from the Fitbit, I had over 70,000 bytes with which I could build an image 88 x 268 pixels in size (see figure 1).

Figure 1

Image Description: Bitmap image made using Fitbit raw data. Each pixel is three sets of hexadecimal values, resulting in a seemingly random, but colorful pattern.



The image in figure 1 is, of course, nothing more than an array of three color pixels—the same as any image taken with a digital camera or scanned into a computer. The only true difference between figure 1 and those images is that the arrangement of pixels in those images make sense to the human brain. One recognizes patterns and sees their grandmother in the photo. In figure 1, I demonstrate the movement that a Fitbit measured from my wrist over the course of 30 days. Is this an any more “true” representation of me than the decoded step data uploaded via the Fitbit program on my laptop? Does it provide any more insight into my EDS than the line graph tracking my sleep cycles on Fitbit.com? It does not.

A number of my colleagues, when presented with figure 1, offered that I had “abstracted” the data, but I disagree. The hex data represented in the 23,584 pixels of figure 1 are no more concrete or abstract than the values which I had intercepted from the Fitbit—they are, in fact, the same exact values. Instead, what I seek to do with a piece such as this is to highlight the abstract nature of the metric being collected in the first place. Who decides what a “step” is? How do they identify a “lightly active” versus “fairly active” versus “very active” step? On a weather forecast, raindrops are present when the chance of precipitation is only greater than a certain threshold—in this case, what threshold delineates between “red” calories

burned, “yellow” calories burned, and “green” calories burned?⁸ I experimented with other forms: an audio file (that sounded much like the noise machine in a therapist’s office), a design in virtual 3D space (figure 2), and a 3D print (figure 3), all of which were built using my Fitbit hex values arranged in different patterns (though in the same order) and surrounded by different meta, or instructional, code. And all of which are useless as a means of training or diagnosis, but also completely valueless to those who may want to appropriate my condition for their gain.

Figure 2

Image Description: A thick line traces in three-dimensions in a computer graphic generated by Fitbit data. Each angle in the link represents a set of three hexadecimal values in the data set.



Figure 3

Image Description: Resulting 3D print of Figure 2 graphic. The lack of proper structural elements such as support posts means that the plastic filament produced a messy bird’s nest of think plastic string.



Inherent Contradictions Within the Quantified Self

I have already reviewed a number of paradoxical qualities of the quantified self movement: the simultaneous focus on self and aggregate and the reductivity of dashboards atop the complexity of datasets. One more glaring contradiction must be highlighted here, however. While quantifying the self is a practice that may trace back centuries (Neuringer, 1981) or even millennia (Swan, 2013), contemporary popular culture’s recent foray into the movement is often credited to an informal meeting of 28 individuals at the home of Kevin Kelly. Kelly, a noted neoliberal technologist, was also founding editor of *WIRED Magazine* and author of *New Rules for the New Economy* (1999) (“History of the Quantified Self”, n.d.).

It is no surprise, then, that so much of the quantified self discourse represents neoliberal tenets: remember 23andMe's consumer-facing homepage with its reminder that there are "23 pairs of chromosomes. One unique you." Or Fitbit's "Why Fitbit" page (n.d.) telling you to "Find your fit" and that "Only Fitbit gives you the freedom to get fit your way." Deborah Lupton (2016) agrees: "Self-tracking," she writes (p. 68), "Represents the apotheosis of the neoliberal entrepreneurial citizen ideal." Neoliberalism, as David Harvey (2005) notes in *A Brief History of Neoliberalism*,

"requires technologies of information creation and capacities to accumulate, store, transfer, analyse, and use massive databases to guide decisions in the global marketplace. Hence neoliberalism's intense interest in and pursuit of information technologies (leading some to proclaim the emergence of a new kind of 'information society')" (p. 3-4).

It seems there is no better place for the neoliberal self to plan its success than in the quantified self movement. And yet, with all of the emphasis on the individual and their autonomy within neoliberal discourse, the quantified self depends highly on the aggregate. Further, an innate trust is required before sending one's spit off to a laboratory or uploading one's minute movements to an anonymous datacenter. For those with an ideological belief in the sovereignty of the self, neoliberals are extremely eager to hand that self over to other parties in order to become one in millions of other database records.

Resolving this contradiction requires a return to Ian Hacking, though this time in his much broader work, *The Taming of Chance* (1990). In the introduction to a chapter entitled "The Autonomy of Statistical Law," Hacking quotes Francis Galton, English Victorian scientist, mathematician, and father of eugenics. During a speech to the Royal Institution in London in 1877, Galton discusses normal distributions—statistical samples which fall in a predictable bell-curve—in relation to evolution. He speaks of "the ordinary genealogical course of race" and how outliers die "away at the margins...the scanty remnants of all exceptional members...revert to...mediocrity" (cited in Hacking, 1990, p. 180). Statistical laws, Galton says:

"Show us that natural selection does not act by carving out each new generation, according to a definite pattern on a Procrustean bed, irrespective of waste. They also explain how small a contribution is made to future generations by those who deviate widely from the mean, either in excess or deficiency, and they enabled us to discover the precise sources when the deficiencies in the produce of exceptional types are supplied, and their relative contributions" (cited in Hacking, 1990, p.180).

Hacking begins his chapter with this passage in order to illustrate how the laws governing statistics extend beyond prediction into explanation—that is, it becomes easy to observe a statistical data set and see cause rather than recommendation (p. 182). If natural selection expects a regression to the mean (or, in the parlance of Francis Galton, a reversion to mediocrity), then both the deficient and exceptional must be jettisoned. Normalization as survival of the fittest, one of neoliberalism's most important ideologies and, in this context, a

pitch-perfect example of Foucauldian biopower.

Neff and Nafus resist the use of biopower in an evaluation of the quantified self:

“While we take the [Foucauldian] scholarship seriously, the clinical view is not an unreasonable one. It argues better decisions are made, physiologically speaking, when standard medical knowledge—the outcome of collective empiricism—is disseminated through the use of self-tracking devices” (2016, p. 52).

Their use of “collective empiricism” here refers to a concept from historians of science Lorraine Daston and Peter Galison as the pair explain a nineteenth century drive towards an unbiased, objective observer in science (Neff & Nafus, 2016, p. 50). Placing the type of data collection and analysis necessary for the success of consumer QS devices in the realm of collective empiricism, however, reveals a reliance on statistical technologies that normalize (the bell curve, regression, et al.). As disability studies scholar Lennard Davis (2006) writes, “The average man, the body of the man in the middle, becomes the exemplar of the middle way of life” (p. 5).

Pain, on the other hand, is exceptional. Chronic illness is an outlier. And to be sure, Neff and Nafus do not deny this. In their account of Nafus’s use of a Fitbit during her rehabilitation from a knee injury, the authors reveal (2016, p. 41) that “she decided that 3,000 steps was an appropriate level of activity for someone with her type of disability”—drastically lower than the 10,000 step standard preprogrammed into every Fitbit device. They go on to note that, in their research, the Fitbit user who had *not* had an injury in recent years was the outlier. Injuries and disabilities are conditions, however, that resist the mean, and, as such resist expression in systems where regression is favored. “Whatever pain achieves,” writes Elaine Scarry, “it achieves in part through its unsharability, and it ensures this unsharability through its resistance to language” (1985, p. 4). The standard off-the-shelf Fitbit or 23andMe package has no language to express a condition such as Ehlers-Danlos Syndrome. It becomes the role of the diagnosed to find a means to express their situation.

Viewed through the lens of an ethnographic practice, however, supplementing data-collection with self-reporting is nearly a requirement. As anthropologist Rosemary Blake (2011) writes:

“The view of the researcher as necessarily subjective has led to the practice of reflexive extrapolations within ethnographic writing becoming almost an ethical requirement (Clifford and Marcus 1986) whereby anthropologists write against the representation of the anthropologist as all-knowing and unbiased. Formerly taken-for-granted notions of knowledge have come under scrutiny with anthropologists such as Michael Jackson using a focus on experience to challenge the notions of ‘determinant systems of knowledge’ (Jackson 1995: 160) espoused in positivist disciplines and sometimes implicit in the anthropological enterprise” (2011, sec. 2, para. 4).

Is there a more positivist practice than the quantified self movement? Rarely, if ever, can one

find a “subjective” practitioner in the rhetoric of QS products and services. Instead, the emphasis is on the autonomous self, using the tools at their disposal to achieve “success” through some sort of quantifiable “experience”.

Further, an ethnographic practice that takes into account that multi-modal representations of the same information will strengthen resistance against the positivist disciplines. If, as Scarry writes, pain (and, by extension, other conditions nearly imperceptible by the QS devices and services) resists language, then our ethnographers must do all they can to liberate that pain outside of traditional language. Documentation of pain or illness will not relieve it biologically. But does the subject seek relief?

Returning to my own condition, I do not. I am fully aware that the way I sit, the way I walk, the things I carry, the frequency with which I carry them—all of these and more will effect the pain I feel. I could track my movements and more with a Fitbit or a notebook or a spreadsheet. I could pinpoint exactly how many pounds I lift in a day or how many steps I take and then try to correlate this to how intense my pain is the next day or longer. Remember, however, that the expression of pain in a means exploitable by the torturer threatens our patient’s subjectivity—something I value more than the relief of the pain itself.

Conclusion

This work is part of a larger project focused on questions of the medicalized self, with a distinct direction towards unsettling the power held by statistics and language, both pillars of the quantified self movement. These pillars are important in building a case for certitude: if it looks and sounds true, it must be. Ethnographic filmmaker, Paul Stoller writes:

“[Jean] Rouch used a “cruel” epistemological acrobatics to tack between the sensible and the intelligible. Perhaps the way to the future of the human sciences is to follow Rouch’s “cruel” path and confront the sometimes inspiring, sometimes fearsome world of incertitude” (2010, p. 133).

It is quite likely that Stoller’s vision of an uncertain sciences is just as utopian as the privacy warnings surrounding the QS movement are dystopian. As an artist and scholar, I am willing to heed both visions.

Tremain (2006) argued that, “Technologies of normalization facilitate the systematic creation, identification, classification, and control of social anomalies by which some subjects can be divided from others” (p. 186). This is an excellent summary of why products like 23andMe and Fitbit—products that rely heavily on the normalizing technologies of statistics such as the bell curve—must be understood through the lens of biopower. Later in her piece, Tremain reminds the reader that it is dangerous to focus so closely on an individualized conception of the disabled person, especially as neoliberalism attempts to use individualism as a smoke-screen for biopolitical control. The kind of reclamation of the self through subversion of QS devices that I propose and attempt here must be seen, then, as a collective goal—not the exercise of downloading and translating Fitbit or 23andMe data, per se, but the understanding

of QS as problematic that comes as a result of this exercise. I offer these Fitbit “hacks” as a starting point to the same sorts of actions taken by the feminist self-health movements of the 70s and those of the AIDS activists in the 80s, and 90s:⁹ the former preached self-experimentation and exploration (Ruzek, 1978) while the latter argued for inclusion in public health discourse through better knowledge of how that discourse operates (Epstein, 1996). Especially in the case of the AIDS movement, finding transparency in the systems of medical research and pharmaceutical development was of critical importance for its success (Epstein, 1996). It is my hope that the opaque and surveillant nature of the quantified self movement that I have demonstrated will inspire a shift away from the willingness with which bodies—both disabled and not—are offered to corporations promising knowledge and freedom.

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Endnotes

1. The preceding describes marketing copy and imagery from the 23andMe.com homepage in May 2016. A review of past homepages—possible via the Wayback Machine at archive.org—reveals that the basic message (“one unique you”) has not changed drastically in the decade since the website first launched.
2. I use the lowercase “quantified self” here, as opposed to “Quantified Self”, as to delineate between a broad cultural phenomenon and a branding effort on the part of its progenitors and device manufacturers.
3. It is, perhaps, a bit controversial to include 23andMe as a product used in the same vein as other quantified self devices and services. On the one hand, the service collects, interprets, and displays a user’s data for the purpose of making changes towards a healthier lifestyle. On the other, the data will never change, and so it does not necessarily allow for “self-tracking”. As the primary “material” of this project is data, the categorizing of 23andMe as a quantified self service makes sense.
4. See 2017 reports that police can request data from services such as 23andMe.
5. Hacking here uses the term *assurantial* to refer to “what Daniel Defert calls a *technologie assurentiel* which has to do with providing [or, assuring] a stable social order” (Hacking, 1990, p. 183)
6. Base-16 numbers are represented by 1-9 and A-F, allowing for digits which represent 1-16. Just like in base-10, which is the system with which is most familiar, multiply the left-most digit by 16 and add to the value of the digits to the right, and so on. For example, 11 = 17, AA = 170. As such, the system can store values ranging from 0 to 255 in just two characters.
7. Every modern computing system is driven by technology which interprets base-16 values as “commands”.
8. Fitbit’s online dashboard changes the color of your calorie burn value based on how many you have burned—from red (low) to yellow to green (high).
9. While the literature on both of these is extensive, for a good starting point, see *The Women’s Health Movement: Feminist Alternatives to Medical Control* by Sheryl Burt Ruzek (1978) and *Steve Epstein’s Impure Science: AIDS, Activism, and the Politics of Knowledge* (1996).

Forum - The Crip, the Fat and the Ugly in an Age of Austerity: Resistance, Reclamation, and Affirmation

NoBody's Perfect: Charm, Willfulness and Resistance

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Abstract: The purpose of this paper is to discuss the representations of disabled bodies on the basis of Niko von Glasow's documentary film *NoBody's Perfect*. Drawing on disability aesthetics (Siebers, 2006) and the notion of crip killjoys (Johnson & McRuer, 2014), it is argued that representations of crip killjoys and their unruly corporeality offer an aesthetic and political context in which the politics of disgust and resentment can be challenged (Hughes, 2015; Soldatic & Meekosha, 2012).

Keywords: disability aesthetics, crip killjoys, willfulness.

Introduction

In this paper, I explore the representations of disabled bodies in Niko von Glasow's documentary film, *NoBody's Perfect* (2008). Von Glasow, who was born disabled due to the side-effects of thalidomide, created *NoBody's Perfect* while looking for eleven people affected by thalidomide to pose for a photography project that aimed to bring visibility to the thalidomide case. Through a darkly humorous touch, this documentary film presents the issues that the twelve social actors had to face during the different stages of their life and their reactions towards von Glasow's photoshoot project. The narrative of the film concludes with von Glasow's unsuccessful attempts to make contact with the pharmaceutical company Grünenthal, that produced the thalidomide drug. I find the material of the representations that *NoBody's Perfect* offers very interesting to discuss as it makes visible the resistance of crip killjoys (Johnson & McRuer, 2014). In this respect, it is vital to explore and discuss the charm of disabled bodies due to the shifting of representations of disabled people in terms of the neoliberal regulatory practices of disqualification and invalidation.

More specifically, I develop my argument that representations of crip killjoys are most needed in our times as they bring forward disability aesthetics and politics with a view to challenging the misleading and divisive representations of "undeserving folk devil" (Briant, Watson & Philo, 2013) that serve the politics of resentment (Hughes, 2015). The charm of disabled bodies and their political value is developed through the key points of: the impact of neoliberalism and neoconservatism on disability and its representations, the examination of aesthetics of disqualification and the importance of disability aesthetics, the practices of looking and staring and the resistance of crip killjoys. In the first section, I outline the shift in the representations of disabled people in the media globally, as this was led by the market-political and moral-political rationality that presents disability as a disgusting matter for the hygienic governmentality in austerity times. In the following two sections, I present Sieber's (2006) work on aesthetics of disqualification and disability aesthetics and their impact on

practices of staring and looking. Drawing upon the notion of crip killjoys (Ahmed, 2010; Johnson & McRuer, 2014) and the analysis of the documentary film *NoBody's Perfect* (2008), I conclude with the argument that the representations of crip killjoys and their unruly corporeality offer the aesthetic and political context to challenge the politics of disgust and resentment.

Disability: A Disgusting Matter for Hygienic Governmentality in Austerity Times

In her analysis of neoliberalism, neoconservatism and de-democratization, Brown (2006) argued that neoliberalism should not only be conceived as the set of free market economic policies that led to the deconstruction of welfare states and the privatization of public services with a knocking effect on the democratic foundations in the North and the South; it should also be perceived as a political rationality, since “it also involves a specific and consequential organization of the social, the subject, and the state” (p. 693). Drawing upon the Foucauldian term, Brown explained that “a political rationality is a specific form of normative political reason organizing the political sphere, governance practices, and citizenship” (p. 693). Neoliberalism, as a political rationality, changes the nature and the definition of the social, the subject and the state, and these changes put the democratic rationality at stake. At the same time, neoconservatism finds ground to expand, adding to the market-political rationality a moral-political rationality that is animated by the desire of a strong state (Brown, 2006) and ignites the flames of populism (Hughes, 2015). In the name of the strong state and the “moral justification,” -where “welfare reform” happens-, the discourse of “welfare burden”, “deserving claimants” (Briant, Watson, & Philo, 2013) and valued/ good citizens flourishes. The exercise and impact of populism on this discourse reinforces and reproduces the politics of disgust and resentment (Hughes, 2015; Soldatic & Meekosha, 2012). Simultaneously, market-political and moral-political rationality has led to a shift in the representations of disabled people in media globally (Briant, Watson, & Philo, 2013; Karagianni, 2017; Soldatic & Meekosha, 2012) in the efforts of sanitizing and moralizing the welfare state from an unruly corporeality. According to Soldatic and Meekosha (2012) disgust is a prominent theme in neoliberal debates:

“The disgusting excessive working-class form shares many properties with the disgusting unruly disabled form. Both sets of bodies are inscribed with normative evaluations that position their bodily performances as abhorrent, revolting and disgusting as compared to the superior social, moral and cultural sensibilities of the middle classes. Disgust is the common thread which ties the excessive working-class body to the unruly disabled body” (Soldatic & Meekosha, 2012, p. 144).

Along similar lines, explaining the development of the politics of resentment within the British context, Huges (2015) argues that the politics of resentment embrace and reproduce a “blame culture”, promoter of the construction of scapegoats. In this context the responsibility of the societal and financial problems created by neoliberal politics is shifted to

the others who live on the margins; disabled people, immigrants, refugees and asylum seekers, homeless people, black and ethnic minority groups (p. 993).

The mass media reinforces the politics of resentment by shifting from sympathetic portrayals to pejorative and stigmatizing depictions focusing on narratives of invalidation and separatism between the “undeserving workless” and the “deserving hard-working”, “counterfeit citizens” and “good citizens” (Hughes, 2015). The pretext of hygienic governmentality, which asserts that “an abject population threatens the common good and must be rigorously governed and monitored by all sections of society,” (Berlant, 1997, p. 175) has served the practices of neoliberal governments well, particularly in relation to “welfare reform” and Brexit propaganda. In this setting, the manipulation and spread of aversive emotion replaced the development of reasoning. Populism mobilized by the elite found ground to indicate the dangerous “others” that take advantage of the hard-working good citizens who desire a strong state and work for it. As Hughes (2015) notes the politics of resentment that mobilize a disgust response to difference and disability serve the formation of a neoliberal state. Disabled people, as well as immigrants, are included in the “underclass” group that is presented as enjoying the benefits of a high life on the backs of hard-working citizens.

As the invalidation of disabled people is not a new phenomenon but rather a reoccurring political discriminatory practice with a long history that constructs the unruly corporeality as the scapegoat, it is important at this point to examine the aesthetics of disqualification and to explore the counterargument of disability aesthetics (Siebers, 2006).

Aesthetics of Disqualification & Disability Aesthetics

The significant presence of disability in arts and culture led Tobin Siebers (2006) to introduce the aesthetics of disqualification and disability aesthetics. Disability has been set as the marker that indicates inferiority and through this process, disqualification. It is the marker of ‘otherness’ that characterises disabled people's existence as less valued and more of a dangerous deviation. Disability also functions as a disqualifier when it intersects with race, gender, class and nationality. Siebers determines that “before disability can be used as a disqualifier, disability, too, has to be disqualified. Beneath the troping of blackness as inbuilt inferiority, for example, lies the troping of disability as inferior. Beneath the troping of femininity as biological deficiency lies the troping of disability as deficiency” (Siebers, 2008, p. 24).

Disqualification relies on the appearance of bodies and particularly on the way that bodies are presented according to aesthetic principles. Basically, disqualification is justified by aesthetic principles. According to Siebers' definition, “aesthetics studies the way that some bodies make other bodies feel” (Siebers, 2008, p. 25). In the term “bodies” he includes not just human bodies but also a range of artefacts, animals and objects in the natural world. Within this range of bodies, the sensation of otherness finds its space and unfolds as “powerful, strange and frightening”. The power of aesthetics relies on the fact that its influence occurs almost involuntarily. Apparently, bodies presented to other bodies cause

feelings that denote an unconscious communication between these bodies. As Siebers states, “aesthetics is the human science most concerned with invitations to think and feel otherwise about our own influence, interests, and imagination” (Siebers, 2008, p. 25).

The aesthetics of disqualification is not just a matter of artistic expression and critique sheltered in museums but should be approached as a political process, since the oppression of minorities derives from their disqualification, which is also determined by aesthetic principles. An understanding of aesthetics is thus crucial because it reveals the operative principles of disqualification used in minority oppression.

The aesthetics of disqualification are dealt within the counterargument that Siebers (2006) calls “disability aesthetics”; a critical concept which shakes down the conception of otherness and exoticism applied in representations of disability as the notion of aesthetics expands to different criteria and values. According to Siebers disability aesthetics brings attention to disability in the tradition of aesthetic representation suggesting that the representation of what is traditionally promoted as the healthy body should not be the sole determination of the aesthetic (p. 64). The concept of disability aesthetics is introduced, not as a means for examining the exclusion of disability from art but as a means for bringing the impact of disability on arts to the surface of academic interest. With his critical analysis on disability aesthetics, Siebers claims that disability has a rich but hidden role in art, and that, by accepting its presence, materialistic notions of aesthetics become richer and more complicated. In contrast, if the influence of disability is rejected then the definition of artistic ideas and works is set as limited. The presence of disability in art requires us to question and revise traditional conceptions of aesthetic production and appreciation:

“Disability aesthetics prizes physical and mental difference as a significant value in itself. It does not embrace an aesthetic taste that defines harmony, bodily integrity, and health as standards of beauty. [...]The idea of disability aesthetics affirms that disability operates both as a critical framework for questioning aesthetic presuppositions in the history of art and as a value in its own right important to future conceptions of what art is” (Siebers, 2006, pp. 71–72).

Disability aesthetics seems to find expression and application though modern and avant-garde art. Most importantly in terms of meaning-making and adding to the shaping of the disability identity, disability aesthetics finds ground and flourishes within disability culture. In this vein, disability film festivals are also the space where viewers are introduced to disability aesthetics and new ways of looking, so all the actions taken in this space should be coordinated towards its fundamental mission. Arguably, changing the ways of looking at disability and becoming familiar with disability aesthetics can lead to the development of inclusive thinking.

In his introduction to disability aesthetics, Siebers (2006) noted that making the influence of disability present in the arts requires a revision of the traditional conceptions of aesthetic production and appreciation. This process will also challenge established aesthetic presuppositions.

The interesting part here is that disability film festivals can expose a variety of looks in the form of point of view in screened films and educate participants about ways of looking. Snyder and Mitchell (2008) suggest that the multiple ways of viewing disability offered at disability film festivals introduce the audience to the politics of atypicality: “The refusal to remain within the strict boundaries of medically and socially prescribed categories of sameness” (p. 14). Viewers are exposed to a variety of depictions devoid of an educational or medical context. Disabled people come on the screen with their stories that in their generality are a close up of numerous human conditions. Documentary films can potentially offer engaged staring encounters where disabled people guide the viewers on how to look at them and in this way, - as Garland-Thomson (2009) notes in her analysis of staring, “Move the audience towards a “newness” that can be transformative” (p. 188).

Gaze, Staring and Disabled Bodies

Repulsive and distasteful or nicely erotic? What would the comments be at the sight of a nude photoshoot of a disabled body? In response to the confusion that the view of a disabled body could cause, Harriet McBryde-Johnson, an American author, attorney, and disability rights activist, stated, “It's not that I'm ugly. It's more that most people don't know how to look at me” (2003, para. 7). Disabled people are regularly subjected to and exposed to different gazes and practices of being stared or looked at.

Initially, the medical gaze was the one that came with the power to regulate “lives worth - or not - worth living”, classifying them in labelled categories and objectifying disabled people to case studies and medical experiments. Disabled people were exposed to this medical gaze from the moment they were born, dealing with normalizing practices that contributed to the construction of “other” in oppressive and painful ways (Clare, 1999; Lapper, 2005). Foucault (1979) called this the clinical gaze and, as Garland-Thomson (2009) comments, it “is one form of person-to-person staring that is highly impersonal, scripted, and asymmetrical” (p. 28) as it is practiced for an invasive visual scrutiny that focuses on isolated elements that indicate pathology. The clinical gaze focused on the pathology and the distinction between normal and abnormal contributed to the production of medical photography and its representations. Millet-Gallant (2010) notes that “nineteenth-century photography produced visual images of pathology and deviance, both corporeal and moral, against which mainstream society could assure their own normality” (p. 90). The clinical portraits followed very strict visual conventions, as they were considered objective medical evidence, and represented human bodies with an aesthetic and discursive detachment. These clinical representations established medical authority over the body and constructed a very particular image of the pathologized and medical body for the public. It is interesting that one of the practices of objectifying the subject of the clinical portraits was to cover the eyes or the face. Even though this technique was applied to protect the patient's dignity and anonymity, it also protected the viewer by preventing a returned gaze (Millet-Gallant, 2010). In historical cases, the clinical gaze engaged a particular hostile stare at people considered degenerated, a stare that Garland-Thomson (2009) calls “the eugenic stare”: “a perverse form of recognizing human particularity in order to extirpate it” (p. 177).

Regulatory and oppressive gaze is the controlling gaze of applied panopticism in asylums, clinics, institutions and segregated schooling. As Foucault (1979) discusses, at these settings of surveillance, “the gaze is alert everywhere” (p. 195) in order to reassure that obedience is retained through the discipline mechanisms and punishment is applied to tackle transgressive actions. Within the settings where panopticism is applied, each individual is “the object of information, never a subject in communication” (Foucault, 1979, p. 197), because the dissociation of the see/being seen dyad is secured. Disabled people were given the position at the peripheral ring of the Panopticon; where “one is seen without ever seeing” whereas in the central tower, those that exercise power on disabled people’s lives, “see everything without ever being seen” (Foucault, 1979, p. 197).

Garland-Thomson (2009) notes that the gaze is different from the stare, as the former is defined as “an oppressive act of disciplinary looking that subordinates its victim” (p. 9), while the latter is “an ocular response to what we don’t expect to see. [...] More than just looking, staring is an urgent eye jerk of intense interest” (p. 3). Staring comes with questions that demand the story of people whose appearance or activity challenge our set expectations and in this way it creates meaning. According to Garland-Thomson (2009), “Staring offers an occasion to rethink the status quo. Who we are can shift into focus by staring at who we think we are not” (p. 6). Staring is a face-to-face encounter between the starrer and the staree where a visual confrontation takes place, bringing various reactions such as engagement, avoidance, mutuality or a combination of these. These reactions derive from socio-cultural and psychological filters, as well as the residuals of gaze traditions that are involved in learning how to look, or how to look away. Curiosity is the genuine response when we encounter novelty but limits of indulging our curiosity are set by socio-cultural and moral rules. Not knowing how to look is the result of the limitations imposed by those socio-cultural and moral rules that regulate not only curiosity but disability too. The face-to-face encounter between the starrer and the staree is a “living communication filled with complex and dynamic interrelations” (Garland-Thomson, 2009, p. 86). As such, it brings valuable knowledge that could cease personal and social anxieties, firstly by teaching us how to look, and secondly by offering the opportunity to interact and think about expanded aesthetics. Garland-Thomson (2009) suggests that experienced starees can guide the starrers to overcome their limited understanding of human variation and the anxiety caused by this limited social awareness. In this context, starees stare back and even make open calls to be looked at.

The management of staring requires the application of interpersonal techniques and communication skills that allow the shifting of the power within looking. Visual and performing arts are powerful mediators that allow this shifting. Social groups that are stared at and have experienced the oppression of clinical, controlling, or colonizing gaze invite viewers to have a good look at them either in performances, photography exhibitions, film screenings or narrative accounts, where they choose how to present themselves and how they wish viewers to look at them. Thus, starees take the lead in directing the staring encounters. This is also translated as an act of emancipation. Garland-Thomson (2009) notes that the “scenes of staring can help us understand our impulse to look hard and our responses to being looked at hard” (p. 94). As scenes of staring, she defines “sites from which interactions arise” (p. 95),

which could be “stareable aspects of human anatomy” (p. 95) such as faces, hands, breasts, bodies.

Documentaries that focus on disability offer rich material of such scenes that invite audiences to have a good stare, challenging them to reflect on the way they look at the disabled body. Viewers are engaged in a mediated but also in some cases a direct encounter with starees and this brings about a new knowledge that has the potential to alter or expand their understanding of disability.

The Charm of Crip Killjoy

When disabled bodies openly and intentionally trouble the narrow and oppressive expectations that are dictated by neoliberal capitalist norms, it is an action of crip willfulness. Crip theory (McRuer, 2006) questions cultural locations and socio-political constructions that reproduce compulsory heterosexuality and compulsory able-bodiedness. One of crip theory’s main principles refers to the construction of an accessible world in opposition to neoliberalism. McRuer pinpoints that access should be understood “both very specifically and very broadly, locally and globally” (p. 71).

A latest development that combines the feminist and crip theory strands is the notion of a “crip killjoy.” Merri Lisa Johnson and Robert McRuer (2014) came up with the concept of “crip killjoy” and “crip willfulness” drawing upon Sara Ahmed’s work on feminist “killjoys” and “willfulness”. Ahmed (2010) examines happiness and socio-cultural instructions for acting happy in an oppressive context, where individuals’ (particularly female individuals’) positioning is fixed, ordered, and imposed, according to society’s perceptions of different social divisions. She specifically notes that:

“The figure of the feminist killjoy makes sense if we place her in the context of feminist critiques of happiness, of how happiness is used to justify social norms as social goods (a social good is what causes happiness, given happiness is understood as what is good). . . . Not to agree to stay in the place of this wish might be to refuse the happiness that is wished for. To be involved in political activism is thus to be involved in a struggle against happiness” (Ahmed, 2010).

Crip killjoys also refuse to fake satisfaction and happiness to justify the current neoliberal social norms that are actually oppressive for disabled people. According to Johnson and McRuer’s (2014) cripistemologies, disabled people are called to deal daily with “the inter-implications of capacity and debility,” which, as in the authors’ cases, led them to “crip willfulness”. They explain that crip willfulness is a refusal to act in accordance with the demands of compulsory able-bodiedness that puts individuals in the oppressive process to disregard their discomfort when they deal with the inter-implications of capacity and debility.

Social norms create particular social expectations that put individuals in a position of dealing with the discrepancy of how they feel and how they should feel. Ahmed (2014) explains that, “Willfulness as a judgment tends to fall on those who are not compelled by the reasoning of others. Willfulness might be what we do when we are judged as being not, as not

meeting the criteria for being human, for instance” (p. 15). The importance of “willfulness” is the transformation of being, when not being (not being white, not being male, not being straight, not being able-bodied) is coming up against being. When crip killjoys become “willful” against the oppressive, ever-present comfort and happiness that is imposed by compulsory normalcy, it is a political decision “to be unstable, incapable, unwilling, disabled,” and this decision “opens up a world of possibility” (Johnson & McRuer, p. 137). In this respect, crip willfulness is an act of resistance to neoliberalism and its practices of abjectification and the political decision of crip killjoys to become willful is a claim for diversity and democracy.

The Charm of NoBody’s Perfect

As mentioned at the beginning of this paper, *NoBody’s Perfect* is a documentary film where the participants, twelve people born disabled due to the side-effects of thalidomide, act as crip killjoys refusing to take the seat that a pharmaceutical company, with heavy historical associations with Nazis’ eugenic practices and experiments, arranged for them. They ask not just the viewers but the public to have a good look at them in order to gain knowledge.

In this film, von Glasow invites eleven adults from Germany and the U.K. to participate in a nude photo project for a calendar publication that will raise awareness of the thalidomide case and compensation claims from Grünenthal GmbH. Even though the idea of this project started as a challenge for von Glasow who also poses for the photo book, to come to terms with his personal concerns about self-image and his disabled body, it develops in to a practice of visual activism. The twelve nude stills showing the models in actual size were exhibited publicly outside the Roman-Germanic Museum (Römisch-Germanisches Museum) in Cologne, receiving comments that cover the two poles of reactions from “nicely erotic” to “repulsive and distasteful”:

“Not repulsive or anything. I think they are just lovely. Very erotic but nicely erotic. A naked man with crippled arms, is really just repulsive. And children walking by can see them. I don't like it. Why? He was damaged by Thalidomide. Why can't he show himself naked? I can't say off the top of my head. Of course I have nothing against Thalidomide victims, but I find it tasteless to show it in public. They're strong people. That takes courage. They must be strong people to show themselves like that” (von Glasow, 2008).

These comments reflect what Garland-Thomson (2009), drawing upon Sontag’s (2003) work *Regarding the Pain of Others*, describes as bad and good staring: “Bad staring leads to the ethical dead end of *schaudenfreude*, of taking satisfaction in someone else’s misfortune” (p. 186), affirming at the same time that “this is not happening to me”. Bad staring fails to achieve the transition from the place of discomfort, shock or fear to empathetic identification. Good staring encloses readings mobilized into political action that allows the development of ethical relations. “If starers can identify with starees enough to jumpstart a sympathetic response that is then *translated into action*, staring turns the corner toward the ethical” (Garland-Thomson, 2009, p. 186).

What also worked as a strong motivation for the participants of Glasow's project, apart from the political action against Grünenthal GmbH that did not respond to compensation claims, is the empowering act of staring back:

Sofia (one of the participants): I've changed sides now. Normally, as a disabled person, you're always being stared at. Now, I am on the offensive. I've done these photos and I'm saying: "Look! Look at me!" (von Glasow, 2008).

Crip killjoys of *NoBody's Perfect* keep getting in the way of various oppressive positioning through the whole film. Mat Fraser, who is also one of the participants, reacts to the publisher's suggestion to offer the revenue from the photo shoot to charity:

Mat: Hold on how they are going to advertise it? "Come and see twelve really sexy, middle age, people, some of them have got weird arms and legs, but you know...whoaaw!! Get the calendar now!", that I am up for but... "Oh! It's such a great project and you'll be doing great things..." I don't want to be part of that! Just because it's disabled people, it should not be automatically a charity event.

Niko: But she likes that because she is going to sell more copies.

Mat: Right, ok. I don't want any of my money to go to charity. I want the money.

Niko: Good, good point.

Mat: Why does it always has to turn to a big orgy of compassion?

Mat Fraser has very sound views on being in control of his actions and choices for participation as a disabled person and actor. He jokes about investing his payment from the project on a "thalidomide toilet" that apparently requires the application of specific technology, making a few points at the same time about disabled people's rights; firstly, by refusing the charity model that immediately positions their lives as being in need and dependence, secondly by receiving payments from the projects they participate in, thirdly by standing by decision making that supports and empowers their independence. Fraser, von Glasow and the rest of the participants, some of whom are also politically active, express very strong political voices and educate the viewers not only on the thalidomide scandal but also on the image of the disabled body and disability aesthetics, illuminating the complexities of disabled people's personalities and lives and, countering a fixed homogenized depiction of disability.

Von Glasow's film serves up the idea of familiarizing the viewers with disability, and includes many slow close-ups on limbs affected by thalidomide initially, and, as the film reaches the day of the photo shoot, the nude models' body parts. The aesthetic of the photo shoot and filming creates an elegant but sensual artwork where disabled bodies are appreciated on the grounds of their beauty, charm, sexiness and assertiveness countering constructed notions imposed by compulsory normalcy. The choice of the aesthetics of nude is also very significant. Much like in cases of feminists' performances, where nude is perceived as a celebration of the female body and an action of "reclaiming it from multiple histories of objectification" (Millet-Gallant, 2010, p. 38), a nude representation of a disabled body supports the originality and authenticity of disability and disabled self and, nothing more

nothing less. Free from projections of guilt and fear, free from normative and oppressive camouflage, the charm of the disabled body is revealed claiming its place in the world of aesthetics and visual activism challenging perceptions.

Von Glasow and his models use their bodies as art to upset the status quo of normalcy confronting an aesthetic economy from which their bodies have been disqualified, excluded and in many cases made freakish. It is a representation of resistance to aesthetics of disqualification and the oppression of compulsory normalcy. An action of crip willfulness. As Millet-Gallant (2010) states:

“The naked body in representation may signify a lack of moral concern and sinful behaviour, and yet such shamelessness may also suggest a freedom from shame or a state of unashamed truth” (Millet-Gallant, 2010, p. 39).

The nude disabled body is free from the applied practices for not passing as disabled. These practices are strongly linked with shame, since they prevent it but also act as reminder of it. Free of markers of disqualification, shame and oppression, the representation of the nude disabled body offers an open encounter with disability aesthetics. This open encounter can challenge established aesthetic presuppositions and change the ways of seeing disability. When the depictions of disabled bodies are clear of the impact of the privileged gaze, they break down the image of the disqualified “extraordinary” body as they expose the embodiment of different types of disabilities and the physicalities of different conditions. Through this approach, the viewers are put in a position of applying good staring and experiencing familiarity with disabled bodies.

Conclusions

In this paper, I have attempted to disturb the pseudo-happiness that neoliberalism and neoconservatism promises through practices of abjectification of the “dangerous others,” by arguing that to insist on making the charm of disabled bodies visible is a required action of resistance that documentary films and disability arts in general can initiate. The representations of crip killjoys offer the counter-narrative, the disability aesthetics and the political engagement to challenge the discourse that populism reinforces in austerity time through the presentation of disabled people as undeserving counterfeit citizens. Already, the cuts in social care funding, the reassessments of benefits claimants, the reduction of funding for employment schemes and the cuts in disability allowances has had a disastrous impact on disabled people even costing them, in several cases that have been silenced, their own lives. Beresford (2017) recently accused the British government of waging a war against the disabled people based on the latest neoliberal actions and their impact on disabled people’s lives. He stated that when the policies are so catastrophic they are associated with something more visceral:

“Governments and policymakers haven’t caught up with the reality that medical advances and social and cultural changes mean that the nature of who we are as a

population has changed. There are now many more disabled people. Making our lives increasingly difficult may kill some of us, but it won't seriously change the maths.

The failure of policymakers is that so many disabled people still face appalling and increasing barriers to employment, education, training, family and social life. It's not getting rid of us that welfare reform should be about, but about challenging and ending these attitudinal, institutional and cultural barriers" (Beresford, 2017, para. 16–17).

It is therefore in these times, more than ever, when austerity is used as the wrecking ball of de-democratisation that knocks down human rights and any sense of social justice and welfare state, that the visibility of cripple killjoys and actions of cripple willfulness should be prominent in education, arts, disability and body politics. The lack of understanding the disability politics and the willfulness of unruly corporeality has created a gap of knowledge that populism takes advantage of in order to shift the image to the support of the politics of disgust and resentment. In this regard, against the homogenization imposed in the name of a "strong and healthy state", the cripple willfulness responds with the political position that *NoBody's Perfect* employs, using disability aesthetics and the politics of atypicality to talk back to the politics of resentment. In this regard, against the homogenisation imposed in the name of a "strong and healthy state", the cripple willfulness responds with the political position that *NoBody's Perfect* employs, using disability aesthetics and the politics of atypicality to talk back to the politics of resentment. NoBody's perfect! Keep willful!

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Forum - The Crip, the Fat and the Ugly in an Age of Austerity: Resistance, Reclamation, and Affirmation

Working to Feel Better or Feeling Better to Work? Discourses of Wellbeing in Austerity Reality TV

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Abstract: By focusing on discourses within the ‘cultural economy’ of reality TV, the following considers the wider positioning of waged labor as essential for mental health during a period of austerity. The findings suggest that discourses of mental health and wellbeing construct figures of a ‘good’ welfare-recipient as one who achieves wellbeing through distancing themselves from the welfare state and progress toward waged work. Framed within the landscape of ‘psycho-politics’, wellbeing and unemployment are arguably entangled to legitimize current welfare policy, placing responsibility on individuals for economic and health security and dissolving concerns over austerity’s systemic impact.

Keywords: austerity; mental health; reality TV

Introduction

Under late capitalism, waged work has become an almost unquestionable activity that the majority of individuals should do for their own and social benefit. A review commissioned by the Department for Work and Pensions (DWP) in the UK argued there are “economic, social and moral arguments that work is the most effective way to improve the well-being of individuals” (Waddell and Burton, 2006, p. vii). Using the lens of disability, activist-scholars have challenged such normative discourses of waged labor (Graby, 2015; Taylor, 2004). Graby (2015) evaluates ground gained by campaigns centered on disabled peoples’ ‘Right to Work’ through the removal of employment barriers. Although noting their significance for increasing disabled peoples’ rights, Graby questions whether inclusion in capitalist structures of employment can ever result in disabled peoples’ liberation. Drawing on Amberley (2002), he argues that a capitalist labor market will never accommodate the needs of all disabled people, instead championing the role of a rights-based welfare system.

Picking up threads of Graby’s (2015) argument, the following article critically evaluates the discursive constructions of waged work and wellbeing during the specific economic context of current UK austerity. This period of austerity has led to a reduction of state welfare, increasing precarity, and as outlined fully below, has been criticized for its negative impact on mental health. At the same time, policy makers continue to stress the role of employment as a precursor to wellbeing. For example, the 2015 UK Conservative government rolled out a new ‘Fit for Work’ service to facilitate employees’ return to work following sickness, justified by the premise that “being out of work has a negative impact on

your health and wellbeing” (fitforwork.org). The mental health campaigning charity Mind has criticized government strategies around work and mental health, arguing that not enough is done to support wellbeing in the workplace (Mind, 2014). Yet Mind was itself criticized for overestimating the contributions waged work can make toward good health whilst remaining uncritical of the ‘toxic assumptions’ behind radically reformed welfare models following the implementation of UK austerity (Void, 2015).

Fiscal Austerity was implemented by the 2010 Coalition government in response to the recent financial crisis, resulting in heavy restructuring and retrenchment of state services including ‘radical’ welfare reforms (Mattheys, 2015). Despite ‘deep-cuts’, improvement to the UKs financial health was slow, leaving economists to label the approach counter-productive (Allen, 2017). Yet the ‘logic’ of austerity prevails. Luongo (2015) argues that the business-finance community succeeded in securing a logic of austerity supporting interests of transnational capital and strengthening neoliberal ideology, positioning austerity as “a site of ideological and discursive struggle” (De Benedictis & Gill, 2016, para. 4) with a key discourse of ‘necessity’ (Lowndes & Gardner, 2016). This discourse of ‘necessity’ gives reductions in welfare spending “a plausible appeal” (Green, Buckner, Milton, Powell, Salway, & Moffatt, 2017, p. 27) and Jensen (2014) notes how welfare cuts are justified through fresh and recycled representations of the ‘feckless’ welfare-recipient.

Nevertheless, even in a culture where austerity is typically unquestioned in mainstream discourse, concern has been raised over its negative impact on mental health (Mattheys, 2015). Mental health difficulties, antidepressant use and suicide have increased post-recession (Barr, Kinderman, & Whitehead, 2015; Frasilho, Matos, Salonna, Guerreiro, Storti, & Gaspar, 2015; Van Hal, 2015), however these effects are shown to be softened in countries that retained strong social safety nets (Van Hal, 2015; Wahlbeck & McDaid, 2012). Austerity’s thinning of such safety nets means less protection is offered against the deleterious effects of the most recent economic crisis. Accordingly, associations have been made between UK austerity policies and declining mental health (McGrath, Griffin & Mundy, 2015), with those at the sharp edge of welfare reforms frequently positioned as at particular risk.

As such, in anticipation of the 2015 governmental budget, mental health workers signed a letter in UK newspaper *The Guardian* proposing that austerity is greatly damaging mental health (“Austerity and a malign”, 2015). Despite protests, the government’s austerity program continued and when the Conservative government came into power in 2015, their first actions were to reduce the household benefit cap and freeze working age benefits (Beresford, 2015). This new round of cuts, alongside further devolution of powers to local councils, is said to have led to ‘super-austerity’ (Lowndes & Gardner, 2016).

It is reasonable to question how, given the apparent weight of evidence of the negative psychological impact of austerity, the economic policy itself has remained relatively intact. Friedli and Stearn (2015) argue that the adverse mental health impact of austerity has been modulated by a reformulation of structural issues such as poverty and unemployment as reflecting individual ‘psychological failures’ and ‘bad’ attitudes. They note how individuals

must “modify attitudes, beliefs and personality...through the imposition of positive affect” to improve their own situations; most notably through the attainment of waged work (p. 40). This follows an individualizing trend characteristic of neoliberalism (Rose, 1992; Scharff, 2005), where late twentieth-century concepts such as ‘empowerment’ and ‘consumerism’ have created narratives of personal responsibility (Harris, Wathen & Wyatt, 2010). Although the roots of individualized health narratives are embedded in discourses that predate current austerity, it’s argued that austerity plays a particular role in consolidating the positioning of individuals as responsible for maintaining their own wellbeing. Firstly, austerity has allowed for a furthering of neoliberal ideals with emphasis on a reduced welfare state and increased privatization. Further, since the current period of austerity, levels of social inequality have increased (Cavero & Poinasamy, 2013). As such, it’s conceivable that increased focus on individual responsibility helps interrupt connections between social and health inequality that could critique austerity policies as Friedli and Stearn (2015) suggest.

Jensen (2014) argues that to criticize welfare policy, we must first understand the ‘cultural economies’ that form and legitimize welfare ‘common sense’. To consider how dominant discourses of waged work, welfare and wellbeing are constructed during a period of austerity, the current research analyses narratives found within a subgenre of reality TV known as ‘austerity porn’ (Allen, Tyler & Sara De Benedictis, 2014) or ‘austerity reality TV’; a genre said to be rich in neoliberal and austere values contributing to anti-welfare discourse (Jensen, 2014; Jensen & Tyler, 2015; Vander Schee & Kline, 2012). Biressi and Nunn (2012) note how reality TV has sustained the attraction of large audiences, altering the ‘terrain’ of factual programming, therefore placing reality TV as a valuable site for exploring everyday discourse. For example, Channel 4’s *Benefits Street*, a British TV program following the lives of residents living on one street in Birmingham claimed to be infamous for high unemployment, drew audiences of 4.3 million, becoming the channel’s most watched show in the weeks aired (“Weekly top 30”, 2014). Jensen (2014) notes that the preferred ‘figure’ (see Tyler, 2013) of such programs is the ‘skiver’, remodeling social problems into problems of individual welfare dependence and irresponsibility. Negra and Tasker (2014) explain that this focus on individuals means anger is deflected from austerity’s structural problems and targeted instead “toward class peer groups who are imagined as retaining undeserved ‘privileges’ in a time of austerity” (2014, p.1).

However, Beresford (2016, p. 422) argues the subtext of ‘austerity porn’ can be “ambiguous and complex”. ‘Implicit’ forms of austerity reality TV appear to be concerned with showing the difficult ‘reality’ for welfare-recipients rather than the obvious shaming and ‘othering’ within more researched examples (Beresford, 2016). They are considered “well meaning”, if “ill-conceived” (Collins, 2013, para. 2). For example, BBC’s *Great British Menu Budget* aimed to be “packed full of great economical cooking on unfeasibly tiny budgets” whilst “changing the way we think about hunger and poverty” (“BBC One prices”, 2013). Beresford (2016) observes how such programs tell ‘sad stories’ that continue to reduce issues of welfare to an individual level, offering no substantial strategies for change.

Austerity reality TV research has mainly focused on ‘explicit’ forms, such as *Benefits*

Street with Kelly (or ‘White Dee’) the analytic figure of choice (for example see Allen, Tyler & De Benedictis, 2014; Runswick-Cole & Goodley, 2015). Following Beresford (2016), the current research analyzed both ‘explicit’ and ‘implicit’ examples of austerity reality TV to explore how more subtle examples of the genre fit alongside the more overt.

The current analysis includes narratives where individuals show any period of negative affect. This broad scope allows an understanding of how affect is positioned in relation to welfare during a period of austerity following Friedli and Stearn's (2015) concerns that affect has become weaponized within welfare policy. By providing an in-depth discussion of mental health and wellbeing narratives within ‘implicit’ and ‘explicit’ examples of austerity reality TV, the analyses hopes to understand the dominant construction of waged work, welfare and mental health. The identified discourses can help understand how waged work and wellbeing are co-constructed, and whether concerns over austerity’s negative impact on mental health are dampened by shifting the focus from structural concerns onto individuals, responsabilized for their own life biographies (Rose, 1992; Scharff, 2005).

Methods

This study used a discursive analytic framework, applied to ‘implicit’ and ‘explicit’ examples of austerity reality TV. The research aimed to include examples from the five most watched public broadcast television channels¹, however no examples from ITV fit the inclusion criteria.

Sampling Decisions

Programs considered for analysis were first aired in the UK from 2010 (the beginning of the current austerity period). Following a description of austerity reality TV by Allen, Tyler and De Benedictis (2014) programs employed non-actors, appeared improvised and non-scripted and were made in a documentary ‘style’ related but distinct from documentary realism (see Jensen and Ringrose, 2014).

Due to the research aims, programs were included that featured an individual experiencing or who previously experienced a period of psychological distress or negative affect. So the semantic coherence of the samples was preserved, all scenes in one episode/series involving the individual were analysed as one ‘narrative’.

Chosen Narratives

Twelve narratives were analyzed; six included explicit mentions of past/present mental health difficulties including anxiety, depression and Post Traumatic Stress Disorder (PTSD). Six narratives included examples where individuals undergo a period of negative affect shown through physical displays of tears, expressing how they felt ‘shit’ or ‘depressed’ or through concern shown by others for their wellbeing (Table 1).

Analytic Process

The analytic process utilized both Foucauldian-inspired discourse analysis and constructivist grounded analysis heavily influenced by Willott and Griffin (1997). Their method allows data and theory to be considered side-by-side, whilst considering the historical contexts that produce/reproduce discourses. After breaking down transcribed data into 'chunks', 'chunks' were assigned codes consisting of a single or few words that described 'in-vivo' themes. Examples of recurrent themes included 'benefits' and 'anxiety'. Each theme was considered in turn to discern the different ways the theme was 'talked about'. This allowed significant patterns to be identified, and these 'discursive patterns' were then considered across themes. Following Willott and Griffin (1997), when considering such 'discursive patterns', previous literature was consulted to move the analysis beyond Grounded Theory influences by allowing room for interpretation.

Once all themes from all narratives were reviewed, key 'discursive patterns' were chosen for further analysis. These were discourses that 'loomed large' in the data and/or enabled the research aims to be addressed. Theoretical accounts of the discourses were created by considering the key discursive constructs of historical enquiry/genealogy, power and subjectification as suggested by Arribas-Ayllon and Walkerdine (2009).

Findings

Claiming to Claim: From 'Can't' to 'Won't' Work

The analysis found that representations of mental health were often made visible, alongside physical disability, to help sculpt the dominant discourse of the welfare 'malingerer'. For example, Phil from Channel 5's *Can't Work, Won't Work* receives employment support allowance and disability allowance for multiple health conditions including Post Traumatic Stress Disorder (PTSD). Phil is positioned as refusing to take action to change his circumstances, believing he is entitled to more welfare. The narrator maintains:

"The ex-soldier claims he's not able to work because of various health issues, so he claims employment and support allowance" ('Can't Work Won't Work', Channel5, January, 2015).

Similarly, in *My Big Benefits Family*, the narrator says of Grandmother Annette with multiple health disabilities, including depression, "She says she's simply unable to work" ('My Big Benefits Family', Channel5, January, 2015). Both these examples position individuals as receiving welfare because *they* say they need to and not because of any independent assessment. This isn't to suggest that individuals aren't best placed to evaluate their own lived experiences, but when positioned in the dominant expert-led discourse of health, this absence of professional corroboration could be seen as delegitimizing Phil and Annette's assessments of their health.

Runswick-Cole and Goodley (2015) analyzed the narrative of Kelly ('White Dee') within Channel 4's *Benefit Street*. The narrative made frequent reference to Kelly's mental health difficulties whilst at the same time focusing on the non-paid care work she does to

support her neighbor, arguably emphasizing her ability to 'work'. Like Kelly, Phil and Annette's narratives show them partaking in informal work. Annette cares for a large family whereas Phil volunteers for a food bank. Reminders of Phil's volunteering are actively positioned next to mentions of ill health as the narrator explains how his health "hasn't improved" but he is "still helping at the local food bank." The honing in on Annette's ability to look after others and Phil's capability as a voluntary worker is arguably used to confuse the boundaries between those who 'can't' and 'won't' work, placed alongside an overall lack of direct representation of mental health difficulties affecting individuals' day-to-day activities.

Building on Runswick-Cole and Goodley (2015), we argue visibility is given to mental health and wellbeing not only to construct a 'malingerer' discourse, but to also shape the 'good' welfare-recipient. Several narratives analyzed involved individuals undergoing a 'transformation', a trope often identified within reality TV (Ringrose & Walkerdine, 2008; Skeggs, 2009), positioning them along a journey of change from welfare 'dependence' toward employability and independence. Such narratives contained a 'feel good TV' texture, yet it's argued that affect is mobilized within the transformations to support dominant discourses of austerity wellbeing.

Working to Feel Better/Feeling Better to Work

Certain psychological states were made visible during specific moments of individual narratives, depending on their place within their 'work journey'. 'Worklessness' was often associated with negative affect. For example, a lone mother from the *Future State of Welfare* explains "I can't get a job so I'm sitting in the house depressed" ('Future State of Welfare with John Humphreys', BBC2, October, 2011). In contrast, positive states were associated with progress made toward employment. Maria from *Life in Debt Valley* notes how she has good and bad days, but the day she attained employment was "a bloody good day" ('Life in Debt Valley', BBC1, March, 2016). For welfare-recipient Vanessa from *Benefits Britain 1949*, her mother remarks how waged work would "help her state of mind...because, like, she's got summat new in her life" ('Benefits Britain 1948', Channel4, August, 2013).

Midway through Vanessa's narrative, she is filmed crying following a day's work experience at a recycling plant, cut short by a bout of pain caused by fibromyalgia. Although there's potential for the program to weaponize this as a form of malingering, Vanessa's disability was used to assist a different discourse. It was suggested to Vanessa that, although manual work was not an option for her, she was able to partake in 'light office work', and an appointment for her was made at a recruitment agency. Consequently, no reasonable adjustments were needed to support Vanessa retain work in an environment such as the recycling plant, a job she started enjoying, and instead Vanessa moulded herself until she was suitable for her new destined role. This involved undergoing a physical transformation after being told her usual attire was not appropriate for work in an office. Vanessa concluded:

"I can't wait to be putting a wage on the table, earning my keep and not having to be dependent on the welfare state ... it's going to be a real buzz for me".

For Vanessa, movement along the journey toward waged work was achieved through her own transformation, resulting in an implied elevation of mood. Vanessa has become the ‘good’ welfare-recipients, or “the active welfare subject” who is “a figure of aspiration, a transformation possible only via coerced self-improvement” (Wright, 2016, p. 2).

David’s narrative within BBC’s *Saints and Scroungers* contained another example of this integration between work and wellbeing. The program differentiates between the “benefit thieves” and those “who actually deserve help” (‘Saints and Scroungers’, BBC1, February, 2016). Positioned as a ‘Saint’, David’s narrative contains a series of interviews between himself and the narrator where David recounts two periods of depression. The first, he explains, was overcome through discovering an exercise class he first attended and then instructed (presumably self-employed). Upon sustaining an injury, David could no longer teach and entered a second depressive phase. It was hinted that the injury was in part his own fault, as he remembers “who can I blame for it? And the only person was myself. My body was constantly aching with the exercise, so I didn’t recognize the signs”, subtly positioning David as responsible for mitigating the consequences of unemployment. He explained how he was “sat at home, feeling sorry for myself”, “didn’t know what to do” and was “totally self-centered” until he imagined a new business idea. As the show’s presenter visits David’s new place of work, he remarks, “This is your reality now... this is where we are after those dark days”, encapsulating the discursive positioning of work as having a direct impact on mental health. David’s narrative not only shows how work is positioned as having a positive impact on wellbeing, but before this could actualize, David needed to stop feeling ‘sorry’ for himself. Any space to consider the emotional impact of suddenly being plunged into precariousness through changes of health was paved over, with David seeing himself as being ‘self-centered’ for lamenting his lost career. A quick and visible shift in David’s psychological state was positioned as necessary, suggesting a change in his frame of mind helped him progress in his journey toward the waged work – a light at an end of the tunnel.

Tammy’s narrative in *The Fairy Jobmother* contained a similar ‘therapeutic’ process. Hamad (2014) has previously noted the therapeutic role *The Fairy Jobmother* (Hayley) occupies. They note how Hayley “counsels participants in emotional and psychological terms, typically providing an empathetic tactile affective display in response to a solicited tearful breakdown” as an ‘epiphany’ which reveals the ‘root cause’ of worklessness (p. 234). This was clearly apparent within Tammy’s narrative, who at first shows resistance to the work experience she’s instructed to perform. Tammy’s ‘negative’ attitude is reformulated through a ‘therapeutic’ realization as she is made to confront this ‘negativity’ by Hayley who insists, “You look for the negative in everything...I don’t understand why,” to which Tammy replies, “I haven’t got that much self-esteem...Cus I was bullied throughout at school” (‘The Fairy Jobmother’, Channel4, July, 2011). This exchange opens up a key area for change - Tammy’s self-esteem. Fitting with the dominant discursive pattern that ‘work is good for you’, taking steps toward waged work is positioned as necessary, as Hayley notes waged work means people can “feel better about themselves”. Toward the end of her narrative as Tammy finds a

voluntary portion within a Sure Start Children's Centre, she notes, "I've changed in my person a lot. I've put my barrier down. I'm accepting help from people. Yep, new, positive Tammy."

For *Great British Benefit Handout's* Racheal, confidence was framed as the psychological barrier preventing her from securing waged work. This is despite the manager of a fitness club where she volunteers acknowledging he would employ her "in a heartbeat" because she is "committed, on time, great with the people" ('The Great British Benefits Handout', Channel5, 2016). Racheal is nonetheless instructed to work through her confidence 'issue' with psychologist Honey Lancaster by entering local businesses unsolicited to leave her curriculum vitae (CV).

Both Racheal and Tammy's narratives suggests that a 'therapeutic' process enables the psychological change needed for individuals to progress in their journey toward work. Yet this is called into question as both individuals are also instructed to *perform* their positive affect. When Tammy undertakes a day of work experience at a homeless shelter where she is serving food, she voices concern that this form of labor feels very distant from her social work ambitions and shows physical discomfort as the smell of the food makes her feel nauseous. The 'Fairy Jobmother' views this as a marker of how little Tammy 'cares' and instructs her to perform 'service with a smile.' For Racheal, as she is handing out her CV to a local business, psychologist Honey notes:

"She's really sort of not being very warm and personable. but that's why this is so important for her to get some chances at practising doing this, so that when there is a job she really wants to go for, she actually comes across as a bit more confident."

These narratives normalize two key related proponents of neoliberal work highlighted by Couldry (2008) of emotional labor and surveillance. Couldry (2008) notes how as emotional labor is expected in the workplace, much of this will be performative as employees are required to not only do their jobs, but portray the relevant expected feelings required by the labor process. The possibility of permanent workplace surveillance means there is more pressure on employees to 'deep act' such feelings (Stagg, as cited in Couldry, 2008, p. 6), meaning they need the ability to convincingly 'play the part'. In these examples, the performative is presented as an important arena for self-work where being able to 'act' in ways that show the right feelings helps the formation of the 'good' welfare-recipient. The proposed deep psychological changes that the search for work can bring about are then sidelined within the transformation process, placing the securing of employment above or at least on par with the therapeutic process itself.

She's Just Not at a Point yet Where She Can Truly Move Forward: Happy Endings, But Only for Some

The findings this far suggest improvement to wellbeing can be achieved through the journey toward waged work, but also that this journey requires self-work in order to reach the appropriate stage of positive affect required to become the 'good' employee. Yet not all narratives concluded with 'happy endings' (attainment of waged work and psychological relief). This reserving of 'happy endings' only for some helps consider the self-management practice austerity rewards and the psychological regulation necessary to 'succeed'.

For example, Sue's narrative within *The Fairy Jobmother* abruptly ends when she is unable to continue the work-club due to declining mental health. *The Fairy Jobmother* concludes:

"She's just not it at a point yet where she can truly move forward, and I have to take that on board and respect her decision" ('The Fairy Jobmother', Channel 4, June, 2011).

To 'truly' move forward, an individual must find waged work, deflecting value away from the improvement of wellbeing for its own sake. It was emphasized that ending the work-club was Sue's decision, leaving little room to consider how austerity's pressure to secure waged work may affect mental health. Instead Sue is constructed as losing hope and it's implied that wellbeing should only be pursued if it has some relation to waged work.

Bill's narrative from BBC's 'Secret Life of Work' had the main affective component of anger, resulting from unfair dismissal from his railway job. Bill shows little psychological investment in the search for *new* work and simply goes through instructed motions, contrasting with the discourses above that reward the committed, conforming individualized job seeker. Bill however is active in the instigation of collective action to get his job back, and contacts old colleagues to picket against replacement agency workers. This act of collective organizing is repeatedly deligitimized with the narrative lingering over a phone call where a colleague declined to join the action and emphasis placed on the lack of official union support Bill receives, and the protesters alcohol consumption. Bill's narrative comes to an end as the narrator concludes:

"Bill's story has also moved on... He fought so hard for his job, because he thought he might get it back. He now know that's not going to happen" ('A Life Without of Work' BBC2, October, 2010).

Here, 'moving on' implies that a future is dependent on him letting go of anger and collective organizing, suggesting that welfare-recipients benefit from being compliant to government welfare programs. This distinguishes any challenge to austerity job loss, and turns the focus away from collective struggles and onto individual decisions.

Both Bill and Sue's narratives suggest the only way of 'moving forward' is through navigating the affective states that allows an individual to partake in waged work. Similarly, in Channel 4's *Keeping up with the Khans*, Bug, who has a history of PTSD shares:

"I want to be off benefits eventually. I want to be independent...to feel like I've achieved something in life and I've given back to the community" ('Keeping up with the Khans', Channel 4, February, 2016).

Bug recounts his past as an environmental activist, and he currently organizes community litter-picks. Despite this, his reliance on welfare means Bug cannot position himself as 'independent' or as 'achieving' enough in life, again showing how one's value is best attained through waged work.

Discussion

The findings show how the narratives analyzed weave relationships between wellbeing, welfare and waged work. Therapy and job searching become entangled as psychologists act as job coaches (as seen in Rachel's narrative) and job coaches as therapists (as seen in Tammy's narrative). This relationship is captured within two main discursive threads. The first positions work as necessary for wellbeing (*working to feel better*) as shown for example in Maria's narrative (BBC's *Life in Debt Valley*) who described the day she found work as a 'bloody good day', or David's narrative (BBC's *Saints and Scroungers*), who sank into depression when waged work was lost. However, research suggests the relationship between work and wellbeing isn't so straight-forward. Butterworth, Leach, Strazdins, Olesen, Rodgers and Broom (2011) found that, although on the whole their participants in waged work reported higher levels of wellbeing, those in *poor quality* work were more likely to experience poor mental health than those in receipt of welfare.

The second discursive thread suggests individuals need to work on themselves in order to attain the right affective states that will help them progress along a journey toward waged work (*feeling better to work*). Individuals need to stop 'feeling sorry for themselves' (David), to get a 'buzz' from the prospect of waged work (Vanessa) and let go of the past (Bill) otherwise they cannot 'truly move forward' (Sue).

Allen, Tyler and De Benedictis (2014) argue that narratives within reality TV can help unpick the key questions "What counts as labour? What counts as work? Who and what has value and is value?" (Section.5.4). These questions are held at the forefront of the following discussion, whilst keeping the lens focused on the politics of austerity.

When is Work Valued?

The narratives position 'work' as contributing to better wellbeing, yet what makes 'work' valued appears 'slippery' and in need of negotiation. Perhaps counter intuitively, it's argued flexibility allows the boundary between the 'good' welfare-recipient and the welfare dependent to be more frequently drawn. For example, Phil's volunteering (Channel5 *Can't*

Work Won't Work) isn't positioned as valued work, made explicit through the program's title, allowing Phil to fit into the narrative of 'malingerer'. For Tammy (Channel 4 *The Fairy Jobmother*), securing a volunteering position is celebrated. In contrast to Phil, Tammy's volunteering is seen as a sign of a changed attitude and as a step toward waged work. Tammy's transformation is shown as a success, despite a lack of any material change of circumstance. This supports Moore (2012) who notes welfare policy aims not to find people employment but foster the 'right' attitude toward employability (as cited in Friedli and Stearn, 2015 p. 41). This 'slippery' definition of work complicates the dominant discourse that 'waged work supports wellbeing', as wellbeing is no longer found within the act of labor itself. Despite this, a relationship between wellbeing and waged work in the analyzed narratives remains intact, and it's argued that this relationship is supported by and supports the politics of austerity.

Wellbeing as Positive Thinking

It is argued that 'work-ready' attitudes have become deeply entrenched in the concept of austerity wellbeing. Friedli and Stearn (2015) note how sculpting a 'work positive' outlook is now common and often mandatory within welfare practice, a concept they call 'psycho-compulsion'. Psycho-compulsion is argued to 'rebrand' unemployment as a mental health issue, where individuals will find work if only they adopt the right attitude.

Psycho-politics² not only changes the concept of unemployment, but shapes the concept of wellbeing itself as it becomes embedded within the theory that legitimizes governmental practises of welfare entitlement. Shakespeare, Watson and Alghaib (2017) assert how the new Work Capability Assessment used to assess individuals' 'ability' to work is based on a model of disability constructed by Waddell and Alyward (2006, 2010 as cited in Shakespeare, Watson and Alghaib, 2017) that overemphasizes the psychological factors associated with common health conditions. Mental distress is positioned as the fruit of 'bad attitudes' and places responsibility onto the individual to change how they think about their health. They argue:

"For most people with common health problems, decisions about being (un)fit for working, taking sickness absence or claiming benefits are conscious and rational decisions, free choices with full awareness and intent, for which they must take responsibility" (as cited in Shakespeare, Watson and Alghaib, 2017, p. 21).

'Responsibility' takes the form of 'positive thinking' and 'changed attitudes' as good mental health is made into an individual choice (Friedli and Stearn, 2015). Even narratives centered on individuals with diagnosed and complex mental health difficulties, such as Annette's (*My Big Benefits Family*) and Phil's (*Can't Work Won't Work*) contained no depictions of mental health support in and of itself. Instead, mental health difficulties can be approached through self-management, which requires a positive attitude and can do spirit. Brijnath and Antoniades (2016) view the move to self-management as 'troubling' for when mental health difficulties such as depression are positioned as a problem within the individual requiring internal change, again we erase socio-cultural factors such as class, poverty and

work inequalities and the State is absolved of responsibility for change (Gattuso et al., 2005; Peacock et al., 2014a; Teghtsoonian as cited in Brijnath & Antoniadis, 2016). People just need the right attitude to use the recourses at their ready disposal.

Atkinson (2015) warns that the current landscape of psycho-politics means wellbeing in government rhetoric has moved from an endpoint of policy and a marker of social progress to a “process factor influencing other desirable policy goals” (p. 48). This has important implications, as Atkinson (2015) asserts, because when wellbeing is placed as an end point, it’s difficult to ignore the impacting structural inequalities. When wellbeing is placed as part of a process toward other outcomes (such as employment), responsibility for wellbeing is moved away from collective responsibility onto the individual. This echoes Taylor’s (2011) caution that the current “concept of wellbeing needs to be treated with caution” as it embeds itself within common trends of individualization and a “marketised view of social provision” (p. 279). Callard and Stearn (2015) note how psycho-politics means individuals are coerced to take responsibility for wellbeing through sculpting the can do attitudes employers favor in spite of the “low pay, no pay economy”, the rise in “precarious, exploitative and part-time jobs” (para. 17) and its likely impact on mental health.

Wellbeing is Independence

The emphasis on the self-management of mental health arguably reflects the neoliberal value given to independence. Several of the narratives conflated independence with waged work and receiving welfare with dependency. Positive affect could be drawn from the expected independence waged work could bring (for example Vanessa getting a ‘buzz’ out of the prospect of ‘earning a wage’), whilst those whose mental health didn’t allow for waged work remained ‘dependent’ on welfare (Bug).

Fine and Glendinning (2005) argue that “autonomy and independence... are promoted as universal and largely unproblematic goals” (p. 602) and that dependency is a State seen as actively needed to be ‘reversed’. At the same time, wellbeing is positioned as a moral necessity as Thornton (2010) explains that hope is fabricated as an “obligatory lifestyle commitment”, necessary to ‘recover’ from poor mental health with a failure to have hope translating into a moral failing (p. 328).

It is argued the entanglement of wellbeing and morality is exaggerated in austere times as ‘good’ mental health signifies a motivated and productive worker, a subjectivity laden itself with moral worth. Wellbeing and independence become intertwined valued constructs, attained through one’s distancing from the welfare state. Taylor (2011) asserts how conflating independence with happiness relies on “normative constructions of the individual and the social” as agency is knotted with ‘independence’ (p. 792). They argue concepts of wellbeing should question that agency can only be achieved through independence, or that the individual is ever separated from social processes (such as entitlement to welfare). As Fine and Glendinning (2005) argue, independence is influenced by the social, with the boundary between independence and dependence more porous than assumed. A more fluid concept of

dependency is one that can be complicated by social barriers, therefore requiring social solutions, going against austerity's logic. Therefore, not only does the logic of austerity remain preserved, but so does an individualistic model of disability.

Concluding Remarks

Reality TV has been positioned as a way of understanding the 'cultural economies' that contribute toward austerity 'common sense' and is a valuable asset to those who wish to critically study welfare policy (Jensen, 2014). The current analysis helps unearth discourses promoting certain ideals around welfare, work, and mental health in the current period of austerity, where wellbeing can only be thought of in its relation to productive labor and productive labor is seen as essential for wellbeing.

A limitation to the research is that the analytic methods are unable to help understand the lived experiences of those the discourses identified claim to represent. They are unable to tap into the psychosocial dynamics of welfare policy where other methods can (see Froggett, 2012; Hitchen, 2016; Hunter, 2015; Stenner, Barnes & Taylor, 2008). However, by exposing the dominant discourses that shape our present and future perceptions of wellbeing and waged labor, we can more critically engage with the construction of the 'good' and 'worthy' welfare-recipient as one who actively strives to detach from welfare and secure wellbeing by proxy through employment practice. We can question why wellbeing has become another condition for citizens to manage so that they can ensure they are 'fit to work' and where the eugenic-logic of austerity may leave those disabled by their mental health.

The welfare narratives disperse discussions over the potential effects of austerity on wellbeing, presenting 'worklessness' as the issue and waged work as the solution. Individuals must adjust, undertaking self-labor to attain the affective state required for employment opportunities needed to sustain wellbeing (Friedli and Stearn, 2015). As Hamad (2014) shares in their own reflections on *The Fairy Jobmother*, individuals 'enact' their own social care (p. 236). Such employment discourse is another frontier of what Rimke (2016) labels 'psychocentrism'; a form of social injustice where correction of individual 'flaws' is favored against economic and structural justice. Friedli and Stearn (2015) note how this rhetoric supports the widening of 'psycho-compulsion' within welfare policy, which unemployed individuals must engage with or risk blame for not improving their own circumstances, despite research suggesting inappropriate work itself can be to the detriment to wellbeing (Butterworth et al., 2011).

Table 1 Character Narratives

Narrative	Original host channel/ year aired	Explicit/ Implicit	Reason for Inclusion
Bill: <i>A Life Without Work</i>	BBC2/2010	Implicit	Experiencing anger after forced unemployment
David: <i>Saints and Scroungers</i> 'Series 4 Episode 14'	BBC1/2013	Explicit	History of depression
Lone mother: <i>The Future State of Welfare with John Humphreys</i>	BBC2/2011	Implicit	Lone mother mentioned feeling 'depressed'
Maria: <i>Life in Debt Valley</i>	BBC1/2016	Explicit	Includes a scene where Maria cries
Tammy: <i>The Fairy Jobmother</i> 'Series 2 Episode 3'	Channel4/2011	Implicit	Tammy is singled out for her 'poor self-esteem 'and 'negative attitude'
Sue: <i>The Fairy Jobmother</i> 'Series 2 Episode 4'	Channel4/2011	Implicit	History of mental health difficulties.
Bug: <i>Keeping up with the Khans</i> 'Season 1 Episode 4'	Channel4/2016	Explicit	Experience of PTSD.
Vanessa: <i>Benefits Britain 1949</i> 'Season 1 Episode 2'	Channel4/2013	Implicit	In one scene, Vanessa appears to be crying.
Joanna: <i>Keeping up with the Khans</i> 'Season 1 Episode 4'	Channel4/2016	Explicit	Described as having mental health difficulties by her boyfriend/ ex-boyfriend.
Phil: <i>Benefits: Can't Work Won't Work</i>	Channel5/2015	Explicit	Experience of PTSD.
Racheal: <i>Great British Benefits Handout</i>	Channel5/2016	Implicit	History of anxiety
Annette: <i>Benefits: My Big Benefits Family</i>	Channel5/2015	Explicit	Experiences depression.

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Endnotes

1. Until the introduction of Free View in 2002, Channels 1 – 5 were the only channels available in the UK without subscription and are still the five most watched UK TV channels. The Broadcasting Corporation (BBC One and Two) is primarily publicly funded through household TV licenses. ITV (Independent Television), Channel 4 and 5 are commercial channels that gain revenue through advertising.
2. ‘Psycho-politics’ used here departs from Franz Fanon’s use of the same term,

which argues that ‘symptoms’ of mental distress are not found within the colonized individual, but are inherent in the structural conditions of colonization . However, Fanon’s concept of psychopolitics also has relevance when considering the effect of austerity as discussed by Mills (2018).

Creative Works

A Conversation about Film, Activism and Social Media with Disability Activist/Filmmaker Dominick Evans

(with RDS Multimedia and Creative Works Editor, Raphael Raphael)

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Abstract: An informal interview with Disability Activist/Filmmaker Dominick Evans. Topics include film and media representation of people with disability and the use of social media in activism.

Dominick Evans is a self-described “trans queer crip director/writer, activist, dad, and nerd.” Dominick’s work delves into inclusion in media, sex education for Disabled/LGBTQIA youth, marriage equality for Disabled people, institutional bias, and LGBTQIA/Disabled reproductive rights. In 2014, Dominick founded #FilmDis, a Twitter chat about Disability in media.



A prolific public speaker who has spoken around the world, Dominick works for the Center for Disability Rights in New York as a Media & Entertainment advocate. Dominick is also a part of the ADAPT media team, and is on the board of Not Dead Yet.

RR: What do you see as the relationship between your creative practice as an artist and as activist?

DE: My activism heavily influences my creative processes. I always seek to work with marginalized individuals, like myself, on all of my film sets. I prefer to work with POC, LGBTQIA folks, disabled folks...we get less opportunities, so I find that often untapped creativity coming together from everyone as something that is so comfortable, fun, and exciting. Some of my early films did not have diverse casts, and that's something I have changed. Our casting is much more open for most of the stories we are telling. The more aware I become of other forms of oppression, the more I want to include in my own work. My film crews have always been very diverse though. Probably because marginalized people are more willing to work with a disabled director.

I create stories that include disabled people in a variety of roles. We are living our lives

all over the world, so why aren't there any disabled characters in background scenes in films? We don't see disabled people in bit parts, supporting roles, or as main characters very much. If disabled characters are in film, we are either the main protagonist or our existence as disabled people serves as a plot device to motivate the action of the nondisabled protagonist. I like to create stories about life that just happen to have disabled people, LGBTIA folks, POC-- or someone who is all of the above--in them. That's influenced by the work I do as an activist.

RR: How does social media fit into your activism?

DE: Social media is a major part of my activism. Part of getting the message out about inclusion for disabled people in films, television, and other forms of media is building up an audience. I have worked to cultivate an audience on social media, which has allowed me to start the discussion about inclusion in ways that involve people all over the world. I don't think I would've been able to get the message out there in quite the same way without social media platforms like Twitter and Facebook.

Social media is a great tool for disabled people to connect with one another, and it has also built a sense of community for disabled activists fighting to change the world both online and off. It's connected us in ways that allow us to work together, and it's created more opportunities for expanding the conversation on inclusion and access for all disabled people.

RR: What do you see, in general, as the impact and potential of film (and television) on the real lives of people with disabilities?

DE: We as a society look to the media to understand things about life we might not have experience with personally. That's why media is so influential on how we treat others. We see the bias of the news and how marginalized communities are treated because of this media. The same is true for narrative film, documentary film, and even animation. So if nobody has ever interacted with anyone who they knew had a disability, their only reference to disability is what they see in the media. Disabled people are not treated very well in any kind of media including film.

What society [takes away] from films that include disabled characters is that disability must be depressing. Disabled people must not be capable of working or doing much of anything. They get this message because disabled actors are not allowed to portray disabled characters. Disabled actors really are kept from portraying any type of character, whether they were written to be disabled or not. We are absent from Hollywood in many ways, so after the film is over nondisabled people don't have to think about us. They don't have to realize how oppressed some of us really are. They don't understand that we are out in the world, trying to fight for access and accommodations. The nondisabled actor portraying disabled characters can leave the role behind and not have to think about disability again, and the audience knows that. They don't have to care about disabled people or disabled issues because they don't see what's happening to many of us. In the

overwhelming amount of cases, they never truly see us.

We really need to see films that involve disabled people in every capacity. They don't need to be films about disability. Just including actors who have disabilities that present visually makes the role a disabled role. It doesn't even have to be a movie about disability, because our lives are so much more than our disabilities. Casting actors who are open about having disabilities that are not usually visible in films (for example, a psychiatric diagnosis may not be visually presented since someone with this type of disability may be able to hide it) also needs to happen to destigmatize disability in Hollywood. Actors are afraid to come out and say they are disabled if they are hiding it, because they will lose work if they do.

It's advantageous to cast disabled actors. We know authentic representation is profitable to Hollywood. The disability community is also a multibillion-dollar spending power. We consume massive amounts of media. If we were given the chance, our films would make money for Hollywood.

RR: Any films people would be surprised to learn that you like?

DE: Wow! I'm not sure what people think of me, so I think most people would be surprised about a lot of the films I like. I think some people would be surprised that I like work by Korean director, Park Chan-wook, especially his film, *Lady Vengeance*. I love most films with Cary Grant in them, but my favorite is *North by Northwest*. I really like films like *Twelve Monkeys* and *Requiem for a Dream*, even if they are not the best representations of disability, and *Cecil B. Demented* and *I Shot Andy Warhol* are obscure favorites. I also really loved the movies *Crouching Tiger Hidden Dragon*, *Hidden Figures*, *The Color Purple*, and *Selma*. Of course, truthfully, I truly do love superhero movies. I'm a big fan of *Captain America*, *Black Widow*, the *X-Men*, and *Black Panther*. Some people might also be surprised to know that the movie I most anticipate coming out in 2018 is *A Wrinkle in Time*. I've been waiting close to 20 years for an amazing film adaptation (the TV movie was terrible).

I have eclectic tastes! You also are sure to catch me watching 80s movies. Whoopi Goldberg in *Jumpin' Jack Flash* is my jam!

RR: Any thoughts on the superhero genre?

DE: I love comic books, and as a certified geek, that love spills over into the superhero genre. I think the superhero genre has many great opportunities for disabled characters and actors. Disability is everywhere in comic book characters and superhero films.

The *X-Men* is a great example, and many disabled people relate to aspects of the comics, shows, and movies. The way that mutants are treated and othered parallels the way many disabled people have been treated and othered. The same is true of the hunting and mistreatment of meta-humans in the DC universe. For the *X-Men* and meta-humans some of their abilities are disabilities. You see that with Rogue, for example. There are also a

lot of harmful cure narrative surrounding the X-Men, which mirrors that of the cure narrative surrounding disability. This narrative is especially poignant in films like X-Men: Days of Future Past, where Dr. Bolivar Trask (played by Peter Dinklage) is literally a disabled person who has his own accommodations and agency, but is leading the charge to 'cure' those with the X-gene.

We see superheroes and villains who use prosthetics or half their bodies have been altered into weaponry, like Cyborg or even Tony Stark who depends on technology to stay alive. You even have characters like Superman who have to have accommodations when they encounter things like kryptonite, which significantly weakens him, Supergirl, and others from Krypton.

I would love to see a physically disabled superhero who has a militarized wheelchair, and they don't need to have superpowers or anything like that. If they have the money of Tony Stark, they could create amazing weaponry that allows them to still be disabled without having to transform themselves or without removing the actual disability. The potential is there for disabled characters to be included. Perhaps I will make a future film that explore this.

RR: What are your thoughts on “disability drag,” non-disabled actors playing characters with disabilities?

DE: First, most disabled people working on disability representation are not really fond of this term. For many it feels very appropriative of gay culture. Some people use ‘cripping up,’ but that still has problematic connotations. I've been calling it disabled mimicry. I'm highly against disabled mimicry. I've never seen an accurate depiction of a wheelchair user or someone with most disabilities. Every once in a while, Hollywood will cast a nondisabled person as a disabled character in a movie where the disability is basically not acknowledged except for a wheelchair, a crutch or some other adaptive device the nondisabled actor uses. They rely on physically depicting the disability through stereotypical actions. Disabled actors don't have to do this. They are simply disabled by existing.

A nondisabled actor can't accurately portray the unique way my body moves as a disabled body. Any attempt to do so is mimicry. It's mockery. A disabled body moves the way it does naturally. It's normal for us. I don't think that's anything you can act accurately. This is problematic because sometimes there will be one characteristic beyond all the terrible characteristics that a disabled person finds somewhat relatable. That still does not make the portrayal okay. It's still causing harm to whatever disability community it's representing. It just complicates things, because we are all so desperate to see ourselves reflected in characters in some way. It makes many disabled people willing to look past all the negative harm these films are causing.

RR: What is the purpose of #FilmDis?

DE: #FilmDis is a Twitter chat that was started as a discussion about disability in the media. It's been active for the past three, going on four years. The purpose is to explore the ways disability in the media is harming or helping the disability community. I think it serves to educate nondisabled people who are not aware of these issues, while giving a voice to disabled people expressing their displeasure, anger, or even joy at portrayals of disability in the media.

#FilmDis has been so successful that we have created a nonprofit, FilmDis, which we are developing into a media monitoring and analysis organization.

RR: Anything else you wish to say?

DE: It's really hard to make films if you are disabled, at least from a monetary standpoint. I am trying to finish up my latest film, Nance + Sydney, and we have to get audio editing, color correction, and some other things. We usually have to crowdfund for our films to even get made. It's really hard to find people willing to support our work, if it's not out in theaters! We don't have big studio support.

So if you are willing to share this, very grateful!

<https://www.gofundme.com/help-us-finish-nance-sydney>

Notes from the Field

Online Professional Development: 'Talking With Pictures': Photovoice - June 2-10, 2018

Genesis Leong
University of Hawaii at Manoa
Center on Disability Studies

University of Hawaii at Manoa, Center on Disability Studies Professional Development summer course is now available. Register through UH Outreach College at <http://bit.ly/CDSphoto> class start on 6/2/2018.

For 25 years, researchers, programs, and activists have used “Photovoice” to engage people with disabilities, patients, youth, families and communities in representing their lives, point of view, and experience using photos, video, art, and writing. Photovoice is a participatory approach to understanding and communication that encourages dialogue and mutual learning. It generates powerful data on health, community, and real lives. It engages participants, professionals, and the public in identifying opportunities for change. It fosters knowledge and awareness on issues of importance to families, communities, and policymakers alike, and helps people to feel their ‘voices’ are heard.

In this interactive online course (a combination of live Zoom sessions and asynchronous work) based on her award-winning in-person workshop, social scientist Laura Lorenz explores the foundations of Photovoice and shares photos from projects she has led in the US and South Africa since 2001 -- with teenage girls, youth living with HIV/AIDS, and adult brain injury survivors. For this course, disabilities from brain injury will serve as a running theme and focus throughout. Readings, presentations, and between-session assignments support person-centered learning and provide hands-on experience working with images and text. By the end of this training, participants will have a solid understanding of a popular approach to participatory health and community assessment, its ethical considerations, approaches to interpreting photos and text, and strategies for outreach. Participants will leave this course with hands-on experience and insights on adapting Photovoice to care, programming, and research intended to engage and benefit people with disabilities, patients, youth, families, and communities.



Seminar Topics Include

- Achieving fair process in healthcare
- Applying Photovoice to clinical work, research, and community engagement
- Adapting Photovoice to different abilities and disabilities
- Interpreting Photovoice data (photos, captions) and options for wider sharing
- Developing a Photovoice plan for use in clinical care, programming, and research

Who Should Attend

- Mental Health Professionals and Social Workers (Beginning, Intermediate, and Advanced Levels)

Other audiences that will find this course useful:

- Evaluators, researchers, rehabilitation clinicians
- Activists, artists, and community organizations

Class Details

Saturday, June 2: 8:00 – 10:00 AM Foundations of Photovoice

Sunday, June 3: 8:00 – 10:00 AM Photovoice Ethics

Wednesday, June 6: 4:00 – 5:30 PM Working with Photos & Captions

Saturday, June 9: 8:00 – 10:00 AM Reaching Audiences

Sunday, June 10: 8:00 – 9:30 AM Planning Your Photovoice Project or Activity

Location: Online (Hawaii Standard Time)

Fees: \$250 (Cancellation deadline: May 25, 2018)

Continuing Education (CE) fee: \$50

For information about continuing education credit, please see www.lslorenz.com(link is external)

Laura Lorenz, PhD, MEd, is a social scientist using innovative approaches to engage patients, youth, and communities in health. A major focus in her work has been collaborating with interdisciplinary teams on programming and research to improve quality of life and function for people with disabilities from brain injury. Before her graduate studies, Dr. Lorenz encouraged community partnerships, project replication, and behavior change through continuing education and photo-journalism in Africa, Asia, Latin America, and the U.S. (For more go to www.lslorenz.com(link is external))

Notes from the Field

Disability Studies 2018 Fall Online Courses

Genesis Leong
University of Hawaii at Manoa
Center on Disability Studies

University of Hawaii at Manoa, Disability Studies Fall Online Courses are now available. Register for both undergraduate and graduate courses through the University of Hawaii at Manoa (UHM) and/or University of Hawaii Outreach College. Classes start on 8/20/2018, reserve your seat today for the following 2018 Fall courses:

Undergraduate Courses

DIS 380 Foundations Disability & Diversity

Focuses on disability as a category of diversity and identity, as well as diversity within disability. Different strategies used to increase the freedom or liberty of people with disabilities are critically examined. This is an excellent foundational course with content applicable and relevant to all fields of study. Instructor Lauren Ho, lauren.ho@hawaii.edu. Online, 3 Credits, 8/20/2018 - 12/14/2018. Register for UHM - CRN 86416 at or Outreach - CRN 1308 at <https://myuh.hawaii.edu>

DIS 382 Accessible Learning Technology

This course covers U.S. Federal Laws and guidelines, accessible technology, creating accessible instructional media, developing long-term resources, advancing accessible social interaction between students and students with instructors, and using case studies as examples of good practices. Instructor Tom Conway, tom.conway@hawaii.edu. 8/20/2018 - 12/14/2018. Register for UHM - CRN 85715 at or Outreach - CRN 1310 at <https://myuh.hawaii.edu>

DIS 383 Disability History and Culture

This Writing Intensive Focus course encourages students to consider disability history and culture in the context of our wider society. Who were the Greeks who created their own society for veterans with disabilities? How does Kalaupapa fit into the history of disabilities? What does Hip Hop have to do with disability culture? Instructor Steven Brown, sebrown@hawaii.edu. 8/20/2018 - 12/14/2018. Register for UHM - CRN 86415 at or Outreach - CRN 1313 at <https://myuh.hawaii.edu>

Graduate Courses

DIS 675C Supporting Multilingual Learners: Science

Evidence-based strategies that support language and literacy skills for English

Learners in the content area of science. Students will study (1) current evidence-based practices for teaching reading comprehension, (2) use and interpretation of assessment tools to monitor progress, and (3) the use of technology to support culturally and linguistically diverse students reading at the K-8 levels. Instructor Caryl Hitchcock, chh@hawaii.edu. Register for UHM - CRN 89372 at or Outreach - CRN 1309 at <https://myuh.hawaii.edu>

DIS 681 Multicultural Issues and Disability

This course provides opportunities for students to develop theoretical and applied family-centered and culturally sensitive approaches to building effective partnerships and facilitating collaborative teams with professionals, persons with disabilities, and their families. Instructor Kiriko Takahashi, kiriko@hawaii.edu. Register for UHM - CRN 83692 at or Outreach - CRN 1311 at <https://myuh.hawaii.edu>

DIS 683 Interdisciplinary Disability & Diversity Issues

Students will develop an understanding about issues individuals with disabilities, their families, friends, colleagues, and allies encounter in today's society. This includes information about the lives of individuals with disabilities and perceptions of impairment; policies and legislation; diversity issues; advocacy issues; service provision issues; educational issues; and how these may be seen through the lens of research and active learning. Instructor Megan Conway, mconway@hawaii.edu. Register for UHM - CRN 83691 at or Outreach - CRN 1312 at <https://myuh.hawaii.edu>

Graduate Certificate in Disability and Diversity Studies

We offer both undergraduate and graduate coursework in Disability and Diversity Studies (DIS), including a 15-credit, interdisciplinary Graduate Certificate in Disability and Diversity Studies. For more information contact Megan Conway, mconway@hawaii.edu or visit www.cds.hawaii.edu/certificates.

Notes from the Field

Call for Presentations: Disability Studies

Genesis Leong

Center on Disability Studies, University of Hawaii at Manoa

It's time to share your most innovative ideas, professional practices, and theoretical knowledge of Disability Studies at the *2019 Pacific Rim International Conference on Disability & Diversity* in Honolulu, Hawaii. We are seeking presenters who offer interdisciplinary insight in the following five topic areas:

Disability Studies and Early Education - *Do you know of or have experience with how labeling children at an early age stigmatize them in the education system? Do you know how we can identify and support young children with disabilities without burdening them with the label of being "different" or "defective"?*

Disability Studies and Education, K-12. - *Do you know of or have experience with strategies and models that are effective for fully including children and youth with disabilities in the general curriculum without losing sight of the need to address individual differences?*

Disability Studies and Postsecondary Education - *What role does Disability Studies play in the academy? How can Disability Studies in the academy transform the way that disability is perceived in higher education and professional practice?*

Disability Studies and Employment - *Do you know what strategies are effective in changing negative perceptions about the value of disabled workers with employers and fellow employees? How can we "raise the bar" of expectations for disabled workers from "getting a job" to "having a career"?*

Disability Studies and Health and Wellbeing - *Do you know or have you experience with how misperceptions about the relationship between illness and disability impact health care and personal happiness for individuals with disabilities? Do you know or have you experience with how social justice issues within indigenous communities intersect with the identification and treatment of individuals with disabilities?*

Disability Studies and Accessibility and Visitability - *How do accessibility and visitability standards and practices reduce the marginalization of people with disabilities? In what ways does accessibility and visitability intersect with poverty, race and language?*

34th Annual Pacific Rim International Conference on Disability & Diversity
March 4 & 5, 2019, Honolulu, Hawaii, USA

Submit proposal by **November 30, 2018** at <https://www.pacrim.hawaii.edu>

For more information about Disability Studies topics, contact topic chair, Megan Conway, mconway@hawaii.edu. For general information on the conference or registration, please contact prinfo@hawaii.edu, (808) 956-8816, fax (808) 956-4437 or email.

Dissertation Abstracts

Compiled by Jonathon Erlen, University of Pittsburgh

Edited by Megan Conway

Triple stigma in forensic psychiatric patients: Mental illness, race, and criminality. West, M. ProQuest Dissertations & Theses, 2015. [Ph.D. Dissertation] United States: New York: New York: University of New York. Publication Number: 3703439.

The experience of caring for an immigrant Latino family member with Parkinson's. Smolowitz, J. ProQuest Dissertations & Theses, 2016. [Ph.D. Dissertation] United States: Minnesota: Capella University. Publication Number: 10159875.

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The mental health of undocumented Latino college students. Mitchell, V. ProQuest Dissertations & Theses, 2016. [Psy.D. Dissertation] United States: California: Alliant International University. Publication Number: 10162040.

The political impact of caregiving - it's a woman's world: An inquiry of the caregiving landscape. Richard-Allerdyce, D. ProQuest Dissertations & Theses, 2016. [Ph.D. Dissertation] United States: Ohio: Union Institute and University. Publication Number: 10294522.

Aversive ableism: subtle discrimination and prejudice towards disabled people. Friedman, C. ProQuest Dissertations & Theses, 2016. [Ph.D. Dissertation] United States: Illinois: University of Illinois at Chicago. Publication Number: 10295505.

An examination of the impact of learning disability status and cultural and linguistic background on pre-service teachers' attributions. Cook, B. ProQuest Dissertations & Theses, 2016. [Ph.D. Dissertation] United States: Hawaii: University of Hawaii at Manoa. Publication Number: 10295893.

The mitigating factors that affect general education teachers' perceptions toward inclusion of students with autism. De Francis, S. ProQuest Dissertations & Theses, 2016. [Ed.D. Dissertation] United States: California: Azusa Pacific University. Publication Number: 10149700.

Madness in the making: psychosocial disability and theater. Wallin, S. M. ProQuest Dissertations & Theses, 2014. [Ph.D. Dissertation] United States: California: University of California, Berkeley. Publication Number: 10150683.

Bodily difference, interdependence, and toxic half-lives: Representations of disability in D.W. Gregory's Dirty Pictures, The Good Daughter, and Radium Girls. Stephenson, B. ProQuest

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The making of the "Fame Monster": Disability aesthetics, bodily deviance, and celebrity culture. Rembis, M. A. ProQuest Dissertations & Theses, 2016. [Ph.D. Dissertation] United States: New York: State University of New York at Buffalo. Publication Number: 10163846.

The constitution of disability in the early United States. Daen, L. R. ProQuest Dissertations & Theses, 2016. [Ph.D. Dissertation] United States: Virginia: The College of William and Mary. Publication Number: 10168231.

Accessing academe, disabling the curriculum: Institutional locations of dis/ability in American higher education. Lucchesi, A. J. ProQuest Dissertations & Theses, 2016. [Ph.D. Dissertation] New York: New York: City University of New York. Publication Number: 10152106.

"Basically intelligent:" The blind, intelligence, and gender in Argentina, 1880-1939. Ellis, R. A. ProQuest Dissertations & Theses, 2016. [Ph.D. Dissertation] United States: New Mexico: The University of New Mexico. Publication Number: 10155447.

Bodies beholden: Intersections of race and disability in literature of the long Nineteenth-Century U.S.. Shipe, C. L. ProQuest Dissertations & Theses, 2016. [Ph.D. Dissertation] United States: California: University of California, Davis. Publication Number: 10182841.