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

My Infectious Encounters as an Autistic Epidemic

Jessica L. Benham, MA University of Pittsburgh

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

Autistic is here on the bus this

Excite, awake,

morning

Illness, Catching the bus at 6 AM,

evil, car headlights wink at me as they bump

rhetorically powerful,

politics makes it so Car headlights caught stimm

mmm Says Sontag (1989)

mmm

mming from me.

The sparkling city my backdrop

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Over the dip

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

Ι	
	"Austerity may
Go	
	be expressed through
To my office	
	bodily affects of fear or anxiety
Trap the ideas in paper prise	ons
	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).

$Ally...is \ \ \text{Someone who feels good about themselves when they speak for me.}$

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).



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

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

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

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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

hallwaydiscussion 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.		
<u>Here, I interrupt</u>		
She reports that		
Reclaim		
	I am anxious, not suicidal	
she has had some symptoms of		
<u>crip</u>		
depression anxiety		
<u>queer</u>		
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). "<u>Not</u> 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.

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

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

Diagnoses

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"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,



disorder 3.) Autism spectrum

"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).

disorder

with features of obsessive compulsive

"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,



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. o*ften 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.

<u>AUTISTIC is in the seminar room.</u> 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). <u>AUTISTIC is at the colloquium.</u> 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 autist 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 Anything else

Jessica Benham, MA, is a doctoral student in Communication, where she serves as a Graduate Teaching Fellow, and master's student in Bioethics at the University of Pittsburgh. She holds a master's in Communication Studies from Minnesota State University and Bachelor's degrees in Political Science and Communication from Bethel University. In addition to her academic appointments and activism, Jessica's research interest lies mainly in the investigation of the rhetorical and ethical constructions of disability in society. She has published articles on the portrayal of disability in media and on experiences of Autism in academia.

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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.