

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

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

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.