

Burrito Texts: Mel Baggs and the Language of Crip Life

Sarah Cavar

University of California, Davis

Author Note

Sarah Cavar <https://orcid.org/0000-0001-8819-787X>

Abstract

Public scholar, poet, and activist Mel Baggs (sie/hir pronouns) died on April 11, 2020 in the thick of a catastrophic pandemic responsible for spotlighting long-held ableist, eugenic rhetorics that literally and figuratively structure disabled life. Since hir passing, however, Baggs's "emblogged" archive — remains powerfully relevant to anti-ableist discourse in an age of COVID-19, laying bare the invisible institutional contours, material and linguistic, undergirding disabled existence. In this article, I will engage with critical texts from Baggs' online oeuvre, what I call an *emblogged* activist archive, written both from within and in the wake of pre-COVID institutional violence, asking what it means to survive/archive against a medical industry built to hasten disabled death. I will explore the ways in which Baggs reveals the discursive architecture of institutionalization, which follows and constitutes disabled subjects — including and especially Baggs herself — both within and outside of hospital walls. Reading renewed interest in the euphemistic language of "triage," "quality-of-life," and "congregate care" through what I call hir "Baggsian Experiential Framework," I will argue that Baggs remixes the language of hir oppression, using new and renewed terminology including the "Nice Lady Therapist," "Snake Words," and the "Burrito Test." At the same time, sie remaps the institution as a discursive condition of disabled life rather than only a discrete(/discreet) location in which certain lives are led. Baggs uses emblogged, queercrip digital space to advance a formidable counter-discourse that has saved hir life and now preserves hir legacy.

Keywords: Blogging, social media, ableism, collective memory, activism, eugenics, disability

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Memory is important.

But your own personal memory is not necessary.

The best of human memory is fallible, changing, and fickle. And memory can fail. In so many ways they can't be counted.

It can be frightening when memory disappears. In all the ways it can disappear.

Temporarily. Permanently.

Memory is not what defines us.

We are still here even when we can't remember.

And the world remembers for us.

Everything we are, everything we have done, everything we have been part of, everything we have affected. Those things are still there in the world.

Our mind may fade or distort or completely eliminate the events but the events, and we in them, are still there, embedded in the world.

Memory is useful, important, valuable. But our memory is not the only memory.

There's a deeper memory, a longer memory, a memory that doesn't require anything of us.

And in that memory, nothing is forgotten, and nothing and nobody is invisible.

(Baggs, 2018k).

At a 2020 Gala by the Autistic Self-Advocacy Network, executive director and longtime autistic activist Julia Bascom took time to honor late blogger, poet, and multiply-disabled activist Mel Baggs, to whom “we [autistics] owe our movement a North Star...[and] owe a debt we can never repay.” (ASAN, 2020) Baggs, whose pronouns, sie (S-I-E, “see”) and hir (H-I-R, “hear”), were chosen in order to draw attention to hir unique sensory

experience of the world, was an anti-ableist social media activist with several blogs, the latest of which, *Cussin' and Discussin'*, I will be focusing on in this article. Baggs died at the age of thirty-nine on April 11, 2020, after a life refusing confinement or simple definition, one in which scholarship, creativity, and life-saving activism necessarily and digitally blended to resist both the rhetorics and physiological barriers posed by institutionalization, abuse, and neglect (and their justifications) by so-called caregivers. Amidst what was at the time of his death a nascent pandemic, in which ableist narratives of “triage” and the rationing of care came to widespread attention, disabled writers’ prescient works gained readers — due, in no small part, to the sudden, COVID-induced destabilization of abled norms — a grim reminder that able-bodiedness is always and already temporary, and that each of us is vulnerable to medico-psychiatric violence.

We disabled people have long acted as “canar[ies] in the coal mine” (Mitchell and Snyder, 38) of neoliberal capitalism, climate crisis, and now COVID-19. The language of *prescience* itself has been roundly criticized by disabled writers and activists, not least via hashtags like #DisabledPeopleToldYou, started by Canadian activist Gabrielle Peters (@mssineomie) and designed to alert abled readers of their willful ignorance of disabled struggles (and a priori delegitimization of disabled knowledge) against systemic ableism, struggles many of those heretofore-abled readers may now share post-COVID (Peters, 2020). Such hashtags occupy an extra-academic space for the theorization of critical disability studies (CDS), the primary framework through which I’ll be analyzing Baggs’s work, which holds that disability is inherently political and socio-culturally contingent, and that ab/normal bodyminds are not born but *constructed* (Meekosha & Shuttleworth, 2009). Further, and with the Disability Justice (DJ) principles of Leadership of the Most Impacted, Interdependence, and Collective Access in mind, I foreground a necessary critique of the university and

governmental co-optation of disability studies, in which only certain individual disabled scholars may produce legitimized knowledge, while others — particularly queer and trans, racialized, poor, fat, and intellectually, developmentally, and psychiatrically disabled people — are largely excluded from scholarly discourse (Meekosha & Shuttleworth, 2009: 50).

With this in mind, I look to just a handful of Baggs's numerous *emblogged*, or digitally embodied through blogging, interventions. I have chosen these among Baggs's numerous writings because they represent some (not all) key examples of coinage and resignification toward collective crip knowledge; that is, the posts I cite constitute not the conceptual limits of Baggs's oeuvre, but starting points for engagement. These are necessarily divorced from (and frequently hostile to) the institution of academia, and grounded in what Johnson and McRuer (2014) call *cripistemological* conceptual and methodological frameworks, derived from the epistemological "backwoods" rather than traditional channels of knowledge-production (128). These frameworks prioritize emergent knowledges that cannot and will not comply with the demands of an academia shrouded in classist ableism, and instead celebrate and explore the potential of un-gatekept, unruly knowledge. Particularly in the face of the mass death resulting from the COVID-19 pandemic, honoring cripistemic forms of knowledge-production becomes not only a crucial anti-ableist intervention, but a materially life-saving one. Specifically, I engage and cite from and within *crip space* (McRuer, 2006; Erevelles, 2011), both literal and figurative alternatives to spaces whose contours are defined and whose substances are (pre)occupied by able-bodied and -minded norms and relationships with reality itself. In doing so, I *displace* heretofore "settled" assumptions about the authority of providers over patients and of "scholars" over "subjects," citing in such a way that refuses the boundary between the latter two. Such interventions are not only crucial to anti-ableist scholarship, but also, now, a

materially life-saving intervention: “listen[ing] to crips about how to handle this pandemic” is of paramount importance in the face of mass COVID-induced disability (Peters, 2021).

Furthermore, it is crucial to inventing a future hospitable to crip freedom and survival.

While not *inherently* digital, cripistemologies find purchase online alongside other forms of disability activist-scholarship. It has been argued elsewhere for the importance of digital, experiential, and identity-based activism for building and strengthening disabled communities, especially those that are also queer and trans (Cavar & Baril, 2021). I follow others who have noted social media as a vital means of activist counter-narration and community building for marginalized populations traditionally gatekept from knowledge production and dissemination (e.g., Jenzen, 2017; Jackson, Bailey, & Foucault, 2018; Kinloch, Penn, & Burkhard, 2020; Ekins, 2021) and denied the rhetorical legibility afforded to “rational” human beings (Price, 2011; Yergeau, 2018). While such work may be dismissed as “armchair-activism,” and thus institutionally devalued, digital activism is a particularly important mode of resistance for disabled activists who are bed- or housebound; in pain; environmentally/chemically-sensitive; immunocompromised; or, as I will explore below, institutionalized by walls or words (Cavar & Baril, 2021). Indeed, Baggs used the blog form as a uniquely effective tool to identify and combat the shared experience of institutional violence often camouflaged as bureaucratic benevolence, not only to educate and (in)form anti-ableist, anti-institutional political movements, but also for self-preservation. With what I call hir *experiential framework*, an interdependent and emblogged approach to activist-scholarship, Baggs used hir status of institutionalization-survivorship to link readers across spacetime, to (re)invent language, and to use blog-based connections as a mode of anti-ableist resistance. Further, the digital medium is itself, literally, life-and-legacy-sustaining for Baggs,

thus providing an opening to engage seriously with emblogged texts as legitimate scholar-activism and with social media as an anti-ableist tool.

In this article, I will first examine Baggs’s analysis of language as both a technique of institutional violence and a vital means of fighting back. Both coining and adopting terms, including “snake word(s)”, the “Nice Lady Therapist” (NLT), and the “‘X’ed” unperson — sie fashioned what I refer to in the title of this essay as hir “Burrito Texts”: digital texts produced in light of ongoing medical violence and incarceration. Then, I will consider Baggs’s 2013 brush with medically-sanctioned murder, and the subsequent deployment of hir own framework toward robust and ultimately life-saving activist effort, as a guidebook for enduring ongoing conditions of crip apocalypse (Piepzna-Samarasinha, 2017), and locate the seeds of anti-normative resistance and movement toward a “new social order” (Robles-Anderson & Appadurai, 2020). Ultimately, I ask: how might Baggs’s experiential framework be deployed in scholarship on and against eugenic practices, both in the midst of, and in the ongoing aftermath, of mass murder through resource deprivation, medical neglect, and organized abandonment? And further, how do hir digital and community-based counter-epistemologies aid in producing and preserving hir legacy?

From Agencies, Toward Agency: Crippling/Cribbing Language

Language is not only a descriptive project, but an inventive one. It carries violent, carceral, and material implications, which are particularly evident when considering the impacts of disability diagnosis on personal agency and personhood itself. Such gatekeeping can be described using Miranda Fricker's (2007) term, "epistemic injustice," and particularly, "hermeneutic injustice," which refers to "when a gap in collective interpretive resources puts someone at an unfair disadvantage when it comes to making sense of their social experiences" (1) — for example, the hiding of or refusal to give diagnoses. Not only are disabled people routinely hermeneutically wronged; we also experience epistemic injustice in the "testimonial" sphere. That is, due to our status as speakers, our attempts to describe ourselves and our conditions are rendered illegitimate and untrustworthy (Fricker, 2007:1). Examples include anosognosia, or a "lack of insight" said to characterize certain psychiatrically disabled persons, and the attribution of tensions with consensus reality to the "delusions" of psychiatrically disabled people (Gong, 2017). Particularly pronounced and understudied are the impacts of epistemic injustice on cognitively, intellectually, and developmentally disabled people, particularly those who use augmentative and alternative communication (AAC) and facilitated communication (FC), which limits both vocabulary access and access to neurotypical frameworks of rhetorical legitimacy (Denome, 2020; Yergeau, 2018: 91-93). Verbality, so long as the correct verbiage is used, reigns supreme.

The rise of social media and other technologies have enabled a variety of disabled subjects not only to digitally travel, share knowledge, and form community, but also for those heretofore barred from access to legitimate "speech" to communicate textually, albeit largely in forms restricted to the neurotypically legible. For Baggs, the blog form was one technology through which sie could reveal everyday rhetorical violence, oftentimes through translation

from hir felt experience to readable text. Crucial to this translation process, in which sie gestured — sometimes literally — toward the gaps left by neurotypical ways of translating, “knowing,” was the coining of new language and the disruptive resignification of existing and often-euphemistic language. Sie did this in order to denormalize and expose the ableist conditions under which sie and others lived. In the following sections, I will look to several of Baggs's terminological interventions into neurotypical (NT) ways of knowing disability, and consider hir digital writings as a radical, emblogged break with and from institutional epistemologies. I argue that hir blog is a (re)birth place for crip resistance to the normative language of “care.” Indeed, while critical care theorists, particularly in the wake of Leah Lakshmi Piepzna-Samarasinha’s (2019) text *Care Work: Dreaming Disability Justice*, have imagined queercrpped genres of feminist, horizontal, and interdependent care, Baggs identifies “care”’s grounding in linguistic and material hierarchies and naming paradigmatic practitioners. Sie draws from hir lived experiences of institutionalization, which began in early childhood and continued intermittently until hir death, to use two critical terms with which to unpack the violence of care: the entwined power of the “Nice Lady Therapist,” “snake words,” the “[person-centered] institution,” and the “Burrito Test” whose collective constriction of embodied/enminded freedom implicate not only experiences of disability but race, class, geographic region, and gender. Using hir experiential framework, Baggs wields the above terminologies to challenge both institutions and their theoretical constriction to physical space.

Cultures at War: The Nice Lady Therapist

First and foremost, the Nice Lady Therapist (NLT), according to Baggs, is a force bent on extinguishing human emotion in order to render bodyminds compliant — all, as coiner Rabbi Ruti Regan (2014) of the blog *Real Social Skills* details — with a smile. Examples of this violence, according to Regan, may include inappropriate touching (sexually or otherwise), educational infantilization, coercive identification of ownership (referring to clients as “my kids”), and punishing expressions of pain, fear, and anger (Regan, 2014). The NLT, Regan notes, is usually a woman, and often acting in a formally therapeutic position. Her occupation, gender, and prototypical whiteness preemptively rescue her from accusations of abuse — this holds not only violent consequences while the abuse is occurring, but also may stymie disabled survivors from accessing resources about trauma, given that such resources typically identify men as paradigmatic abusers — this fundamentally transforms disabled peoples’ “relationship to gender” and understanding of patriarchy (Regan, 2014). In Baggs’s case, it also enables a more capacious understanding of institutional power. Following Regan, Baggs identifies NLTs as both a genre of person and a culture oriented toward “looking nice, never directly showing emotion, sounding bland and detached in a certain way, no matter what you’re feeling or thinking or doing” (Baggs, 2018e). Baggs’s critique follows Regan’s not only in identifying demands for compliance at the expense of autonomy as inherently ableist, but also in locating the NLT’s capacity to harm in *her* particular social location. This care-work, set in implicit and explicit opposition to the crip interdependence Baggs both discusses and enacts through hir blog, is “degrading in ways that are hard to pinpoint” and best described by Baggs’s vivid posts. That is, Baggs deploys hir experiential framework to discuss the ableist classism embedded in the NLT, who provides

and denies care based on assimilationist logics of respectability and capacity for normative behavior.

The cultural norms which produce the NLT and her demands are embedded in white, middle-class, and abled norms; the white woman assimilated into what Baggs calls an “[disability services] agency-middle-class fear of feelings” is here imbued with the power to police “deviant” expressions of emotion — for instance, embodied, visible anger (Baggs, 2018e). For developmentally disabled people, Baggs writes, it is often more difficult to conceal one’s true feelings, communicate with euphemistic tact, or conceptualize immediate feelings abstractly, all trappings of middle-class assimilation presented as “social skills” to disabled youth (Baggs, 2018e). Here, the false language of “care” — specifically, notions of care as always-already benevolent — fuse with paternalistic anxieties about unassimilable or unsightly (disabled) people in order to punish them for non-normative expressions of emotion. As Baggs notes, heretofore class- and region-specific behavioral norms heavily influence the work of the NLT, who exercises her power paternalistically (or maternalistically) to produce conformity, and names conformity as a prerequisite to personhood. Identifying most closely with the classed, regionalized behavior of a “working-class Okie,” Baggs writes of anger one can “see...on [hir] body,” a genre of “pissed-off [...] write into [hir] every movement, a statement which applies to an entire spectrum of emotion” (Baggs, 2018e). As a direct result both of this and hir association with other advocates who tend to “fly off the handle,” Baggs faced threats of institutionalization, emotional surveillance, and ultimately being forbidden from discussing hir lived experiences of medical mistreatment (Baggs, 2018e).

Given that “[NLTs] tend to be terrified of anger...[and] emotion in general,” their impulse is to psychiatrize middle-class values as markers not only of social superiority but

also of *correct* neurotypical perception, pairing abusive behavior with denial of abuse itself. In these spaces, hierarchical power dynamics are collapsed into “friendships,” and “frightening or painful exercise[s]” are transformed into “therapy” (Regan, 2014). As Baggs describes, while the “crude” behavior of the working class/disabled subject disrupts clinical, middle-class norms, the “nice” behavior of the NLT obfuscates discursive and material violence, including, ironically, outright “denials of care” for disabled people (Baggs, 2018e). Caring becomes a form of shaping, chiseling, molding: to “care” is the verb by which disabled, poor bodyminds are brought into the proverbial fold of “carable” community, “rescued” from outcast (and, as we will later discuss, “Xed”) status and from physical institutions.

A combination of experiential grounding and borrowed language render the NLT a sharp tool in Baggs’s hands, not only as a critique of carceral ableism but as a critique of the classed notions of respectability always-already entangled with disability service providers, if one that, given its grounding in Baggs’s white disabled experience, elides a robust critique of race that would have further strengthened the analysis. Here, disability is not inherent to one’s bodymind, but rather, formed with and in relation to already-classed milieus; the same is true for the unequal and violent conveyance of normalizing “care.” Using his blog to expand the concept of the NLT with a working-class perspective, Baggs makes visible the class politics of institutionalization — and, perhaps, middle-class hegemony as an institution unto itself — as well as the dire need to imagine care Otherwise from the institution, specifically, as we will see later, in the non-hierarchical form of crip friendship.

“Person-Centered”: Snake Words and the Language of Violence

As illustrated by the figure of the NLT, violence is endemic to the architecture and definition of “care” itself, which by definition occurs at the whim of the caregiver. But these

violences are not only the province of individual therapists, rather, they are built into a common language shared by a variety of medical/disability service workers, baked into educational curricula and medical and psychiatric programming. Beyond the NLT, a type of *individual* symptomatic of an ableist, classist, and paternalistic care industry, Baggs also revealed the false-sensitivity of so-called “snake words” within disability discourses. These words euphemize the everyday dehumanization experienced by disabled people, especially those in full-time care and those without access to spoken language. Using both blogged and filmed interventions, Baggs reveals the danger of snake words while resisting their underlying logic, which exclusively prioritizes verbal speech over other modes of communication, and honors alternative relationalities instead.

Baggs’s blog engaged intimately with the quotidian and largely unacknowledged denials of autonomy central to hir disabled life; from here, sie observed trends in caregivers’ (ab)use of language to further these ableist denials. In “Developmental Disability Service Agencies: Can’t vs. Won’t (2018i) Baggs describes being given hir bedtime medication at progressively earlier times, based on the convenience of a disability services agency. The agency refuses to administer the medication at the appropriate time, but also refuses to send Baggs reminders to take the medication hirself, forcing hir to take the medication at the whim of the attendant and thereby removing hir autonomy. As with the NLT, what at first appears to be care in fact manifests as violation; part of this violence lies in the description itself. The “person” that “person-centered care” centers does not actually exist: rather, they are the promise of a recovered bodymind against which the apparent “brokenness” of the disabled person is measured. Further, in a compounding use of snake words, the very language of brokenness is also euphemized; Baggs elsewhere describes a shift from the widespread use of the r-word, which overtly marks hir as “less than a thing, something disgusting, [and]

something that shouldn't exist” (Baggs, 2018d), to the language of “*special*.” These shifts constitute a “glamour,” a way of “hiding the dystopia” (2018b) under which disability renders one a perpetually-abusable *unperson*.

While both medical and laypersons can and do fall victim to euphemistic language about disability, such language — and subsequent neglect of patients — is also fundamental to their education. Baggs photographs and describes “person-centered” worksheets brought to hir by caregivers from a recent disability support workers’ conference, worksheets designed, in spite of their name, for caregivers and not disabled people. These worksheets, Baggs notes, emblemize the divide between the rhetoric of “person-centeredness” and disabled peoples’ lived realities. One worksheet, titled “[Mel’s] One-Page Description,” contains blank bubbles in which Baggs is to write which activities, practices, and persons are “important” and “supportive” to hir (2018c). Such worksheets, which direct users to mark bubbles to answer pre-set questions, allow only a narrow range of self-description. They also pathologize everyday activities and relationships, limiting the ways in which disabled people may “correctly” communicate with caregivers, and thus, document their realities.

If the “person-centered” agency’s “person” does not exist, we might look to Baggs’s experiential framework as a form of counter-documentation (documentation authored and authorized by Baggs, not by record-keeping medical institutions), wherein hir evidence of self both reveals the fallacy of the “person-centered” ableist agency and thus retrieves “agency” for Baggs herself. Baggs does this through visual and textual language: in fact, sie initially came to prominence as a digital disability activist through hir viral video, *In My Language*, a resounding critique of the privileging of spoken language and devaluation of non- and semi-verbal modes of communicating, made through the very assistive technologies so often devalued alongside their developmentally and intellectually disabled users (Baggs,

2007). The computer, and specifically the internet, opens new linguistic and relational possibilities such that Baggs can create a counter-discourse to ableist snake words. On and through hir blog, as well as hir YouTube channel, Baggs reimagines the power of untwisted and reclaimed language, using a distinct communication style described by Jellicoe (2021:6) as “careful [and] exploratory.” Jellicoe writes of *In My Language*: “Instead of rushing its point, the film makes us see. It patiently explores the duality of sound and image [...] motions are paired: a swimming human, a flag that rises and falls in the wind” (2021:10). With these images, Baggs recenters the ways of seeing, thinking, and moving denied rhetorical legitimacy. In “hir language,” a new definition of “person-centered” may be born:

Person-centered is supposed to mean that when they decide what support you need from the DD system, everything comes from what you actually need and want out of life and out of the support you’re getting [emphasis added].

It means that rather than forcing you into a ‘support model’, they look at what you need out of life, what you want out of life, and how you can get it. (Baggs, 2018c)

While linguistic interventions like euphemisms and worksheets both conceal and consolidate structural ableism, normalizing the conditions under which sie herself is rendered silent, Baggs imagines a respect for linguistic pluralism that sie express in hir blog posts and video. Rather than normalizing tropes of neurodivergent people as “lost in [our] own worlds” (Yergeau, 2018:8) marking those with non normative modes of communication as divorced from Real (neurotypical) Life, and thus from “personhood” in a “person-centered” context, respect for alternative modes of communication — blogs, videos, AAC, and more — is in fact required for a good-faith person-centered approach. Finally, and as we will consider more extensively in the following section, language — especially that which selectively grants and removes personhood — not only snakes and constricts but also *constructs*

institutional walls around disabled people, including Baggs. And Baggs's ability to talk back against institutional "head games and word games" (Baggs, 2018m) can make the difference between life and death.

The Institution Yet to Recede: Xing and The Burrito Test

The role of institutional violence in disabled life and death has been widely theorized, perhaps most famously by Liat Ben-Moshe, to whose article, "The Institution Yet to Come," which expands and disables Goffman's (1968) conception of "the total institution," and Foucault's (1988) critiques of the asylum, I owe the title of this section. For Ben-Moshe, the institution is not a singular, fixed entity where disabled people "end up," but rather, a specter, a continuously-moving target, and a threat haunting disabled people regardless of status: "the ghost of forced confinement haunts us all," particularly those who are multiply-marginalized (Ben-Moshe, 2013: 132). Cognitive disability activist Cal Montgomery, one of Baggs's longtime interlocutors, further describes institutionalization not simply as a specter but as an inheritance, a legacy, a connection across disabled generations, all despite its isolating ethos (Montgomery, 2001). This is an inheritance of collective dehumanization, wherein the dependent person is excluded from the bounds of personhood at all, and is thus not only barred from accessing the means to their autonomous subsistence but also to the capacity to narrate their lives.

In hir experiential analysis of institutionalization, Baggs makes use of hir "explanatory" and layered writing style, "expanding from a core idea" (the lived reality of institutionalization) to a more abstract analysis of the mechanisms of dehumanization. Sie shares hir knowledge of words as tools and as weapons with activists like Dave Hingsburger, whose theory of the "Burrito Test" heavily influences hir own anti-institutional work. The

theory, which made its debut in one of Hingsburger's direct support newsletters (n.d.) asks readers a simple question in order to determine whether a space is or is not an institution: *can you get up in the middle of the night and microwave a burrito?* Such a visceral intervention into the abstract matter of bodily autonomy reflects Baggs's priorities as a writer and activist, and promotes a more capacious understanding of the institution, not as a building but, especially in a post-deinstitutionalization era, a narrative and relational structure (Mitchell and Snyder, 2018:38-39). Home-based care, which Baggs describes as "independence theater" (2018a) is a form of institutionalization, as are conditions of housing- and food-insecurity. Baggs makes the latter observation in "Why I'd sometimes feel safer dying on a street corner than going to the hospital," (2018j) figuring the hospital, street, and other institutional spaces are figured in parallel as sites of disabled, racialized, classed, and gendered abjection, spaces to offload "disposable" bodyminds. These are spaces which hold what Baggs calls the "Xed," citing the fictional process of soul-erasure Madeline L'Engle details in her novel, *A Wind in the Door* (Baggs, 2017). When one is Xed, they are disappeared from the realm of the cared-for, a nonperson whose existence is without value. As in the case of NLTs and snake words, humanity, here, is selectively ascribed and heavily policed: speech, behavior, and embodiment outside its bounds warrants intentional, organized abandonment. Alongside the Burrito Test model of the institution, Xing — which can be extended not only to the institutionalization of disabled people but to antiblack police murder, to eliminationist anti-trans rhetoric, to the filicide of disabled children, and to mass disabled death during the COVID-19 pandemic — offers a tangible way to map one's own story onto a larger narrative of dehumanization and disposability. It also critiques the standards by which

certain bodyminds are rendered disposable in the first place; this Baggs demonstrates in and through hir blogging.

Given hir own experience of institutionalization, Baggs, in hir opposition to the process of Xing, makes subtle and meaningful moves to connect hir struggles with others'. Sie both brings hitherto "Xed," erased perspectives into disability discourse, and in so doing advocates for intracommunity, cross-disability solidarity, despite longstanding lateral aggression and the marginalization of intellectually disabled people in the disability rights movement. In order to do this, Baggs does not resist Xing by reversing it, by attempting to "prove worthy" those community members marked as worthless. Rather, Baggs places herself among the dehumanized while asserting a digitally public life. Sie presents images and videos such as *In My Language*, in order to establish concrete linkages not only between hir visibly disabled bodymind and hir online life, but also between hir bodymind and words and those of other disabled people without a public platform. Sie marks hir experiences as emblematic of disabled dehumanization, wielding hir writing as evidence of hir disabled experience rather than proof of the hidden, exceptional intelligence of which mental disability advocates are often accused (Yergeau, 2018:32). Baggs moans, flaps hir hands, and poses in front of a therapeutic garden plot, forcing readers to link the prolific writer whose work they consume with the bodymind diagnosed "abusable" — a "patient who doesn't matter" — by medical doctrine (Baggs, 2018j).

Under Baggs's experiential framework, the Burrito Test to personal interactions, documents, and bureaucratic processes: it is not only the walls of the hospital that confine, but also the humans within. Sie also embodies resistance to the weaponized, ableist text. After a blog post recounting a false accusation of physical assault on a staff member after a

disagreement, Baggs describes the transformation of “office gossip” into medical and legal record, and the literal “institutionalization” of ableist lies about patient behavior:

They can write anything about you [...] if someone doesn't like you challenging their power, they have the ability to throw that power around by accusing you of crimes. They don't have to prove you did anything (2018f).

The written word is a weapon of erasure, a means of “disappearing” noncompliant bodyminds. Baggs also enters hir own experiences of institutional violence — particularly through the non-traditional institution of home-based care and services (HCBS), an instance in which the Burrito Test applies outside the four walls of the hospital. Even in the nominally “deinstitutionalized” context of HCBS, “on a deep level involving power and control, not on a cosmetic level where all you've done is slap some new decorations on the walls of the old system” (Baggs, 2018f). Baggs differentiates hir critique of HCBS from others' criticisms of failed-deinstitutionalization, using hir own lived experience as evidence: the services falsely named “community-based” fail not because they are not institutional enough, but because they so explicitly mimic longstanding institutional structures — “the same people at the top all have the same kinds of power” (Baggs, 2018g).

If words are weapons in the hands of ableists, Baggs demonstrates that it can also be a weapon in the hands of disabled people. Writing is the medium through which Baggs deploys hir experiential framework, as well as a demonstration of the humanity — the refusal to be silenced or siloed — of hirself as a speaker. This is the beating heart of Baggs's experiential framework: the awareness that life lives in its telling, and that the telling of the story is in itself a demand for human connection — the connective tissue of what Baggs imagines as a “good agency,” grounded in friendship and generosity (2018h). *Our lives depend on it.*

Conclusion: “If I am killed...”

Mel Baggs's life, extended and mediated online, was a continuous push to exercise autonomy, and to create conditions under which hir personhood would go unquestioned. Writing, “I will no longer pretend that I am not trying to scrabble together some kind of meaningful life living on the ragged side of a nightmare,” sie resisted hir aides’ and the public’s impulses to consider hir a mere “pile of medical problems” and linguistically demote hir to the status of “unperson” based on hir real and perceived needs and limitations (2018l). Instead, sie advocated relational transformation through shared narrative, prioritizing interdependent, non-hierarchical models of caregiving and foregrounding cross-disability collaboration within a broader disability community, especially in light of divisions between “mentally” and “physically” disabled groups (Baggs, 2020). Hir blog posts provide a means of speedy and ungated communication with others heretofore “Xed” by ableist institutions, while also facilitating the crip friendship that, seven years before the COVID-19 pandemic of 2020, saved hir from death-by-medical-neglect. In this conclusion, I step back from the analysis of specific language and turn to the life-sustaining power of radical crip friendship, friendship which was only facilitated by Baggs’s digital linguistic transformation.

On March 31, 2013, Baggs was hospitalized for complications related to hir gastroparesis. Sie made a post on hir Tumblr blog expressing anxiety over what quickly proved to be medical coercion. According to Lydia X. Z. Brown’s summary: medical providers attempted to deny Baggs access to a feeding tube and thus starve hir to death. When sie resisted, asserting hir desire to live, doctors asked whether or not sie was “at peace” for the decision to remain alive (Drake, 2013b). Sie was only surgically intubated after a flurry of calls from disability activists across the country and around the globe, including the anti-physician-assisted dying organization Not Dead Yet (Brown, 2013). News releases by

Not Dead Yet updated concerned readers as to Baggs's situation, quoting from hir blog post update, titled "Oh also wanted to thank all the ppl I don't even know":

Who called the hospital on my behalf. The woman from Disability Rights Vermont who, free of charge, sat through all my doctor visits yesterday. All day long. Etc.

You did have an impact. One of my doctors said there's an abrupt change in my charts starting when ppl started calling and stuff. I noticed too because they turned from hostile to conciliatory on a dime.

Just be aware even if my surgery goes perfect there's lots more patients to protect.
(quoted in Drake, 2013a).

Mel Baggs was prepared for such a crisis, writing hir experiences of medical neglect as part of a broader pastiche of disabled experiences whose deadliness crossed space and time. In 2006, on an older blog called Ballaexistenz, sie made the post "If I am killed," a confession, warning, and manifesto in which sie details the risk of filicide and caregiver murder disabled people, including Baggs himself, frequently face. Sie describes the majority of these deaths as "invisible" — entirely unknown, confined to institutions, or otherwise justified by the rhetoric of "burdensomeness." Here, sie solicits readers, friends, and loved ones to remember hir and other Xed individuals actively, prior to their deaths; to remember that sie "lov[ed] life" and was not a mere object, but a *participant* experiencing its richness (Jellicoe 2021:2). Here, Baggs's story does not only foreshadow deadly ableism in an age of COVID-19, but illuminates and powerfully resists erasure. Such texts not only preserve Baggs's memory, but sow solidarity among disabled readers, expanding a digitized crip network of community care, of which Baggs was a critical component. This is not only a crippled reconfiguration of the Harawayan cyborg, in which the technological medium

realizes hir inseparability from hir readers and interlocutors, but also a mechanism by which words, quite literally, save lives and make afterlives anew.

The relational connections sie formed as a blogger, scholar, and activist, the robust digital network sie built in pursuit of genuine, active cross-disability solidarity would not have existed to sustain hir had sie not cultivated it via reclaimed anti-institutional language. Baggs reclaimed language and rebuilt relationships, ultimately emblemizing the material power of language-based internet activism, and of grounding political work in personal experiences — including the ongoing personal experience of deadly medical (mis)treatment. In doing so, sie not only preserved hir own life but awakened others to the immediate needs of the disabled body politic: it was through Baggs's blog posts that I myself entered into politicized disability identity, and first gained the language to articulate experiences of medical and psychiatric abuse. Baggs's observations of the institutional violence that unites uniquely across disabled generations and lived experiences, sie curated a space of care and honor in which disabled lives and memories could survive, in which new community members could be welcomed-in, and in which, whether in body, word, or both, sie would not be Xed.

Notes

1. While this is not an autoethnographic article, I choose to explicitly identify myself with the “we” of disability community and deploy the first-person when needed throughout the piece.
2. I use “Post-COVID” throughout this piece to refer to any time after the initial global lockdowns of March, 2020, as a shorthand for “Post-[onset of] COVID.” I explicitly do not use Post-COVID to refer to an imagined COVID-free present or a “finished” pandemic.
3. As described by disability performance collective Sins Invalid, available from: <https://www.sinsinvalid.org/blog/10-principles-of-disability-justice>.
4. While I lack space here to further discuss non-rational and Mad modes of communication, engagement with these forms is ripe for Mad study and critical to what I have elsewhere termed “transMad” digital praxis. (Cavar, 2021).
5. In his novel *Lords and Ladies*, coiner and fantasy author Sir Terry Pratchett describes words whose “meanings can twist just like a snake,” noting that, “if you want to find snakes look for them behind words that have changed their meaning.” (Quoted in Baggs, 2018b).
6. For further examples, see the Twitter thread started by Esther Leighton (2021, July 22).

References

- Autistic Self-Advocacy Network. (2020, November 14). Gala remarks from Executive Director Julia Bascom [Videofile]. <https://youtu.be/4y1BAqOnhMM>
- Baggs, M. (2006, April 19). If I am killed... *Ballastexistnz*.
<https://ballastexistenz.wordpress.com/2006/04/19/if-i-am-killed/>.
- Baggs, M. (2007, January 14). *In My Language* [Video file].
www.youtube.com/watch?v=JnylM1hI2jc.
- Baggs, M. (2013, March 31). So I get woken up at seven something in the morning. *Withasmoothroundstone*.
<https://withasmoothroundstone.tumblr.com/post/46772164821/>.
- Baggs, M. (2017, August 22). Holding Onto my humanity. *Cussin' and Discussin'*.
<https://cussinanddiscussin.wordpress.com/2017/08/22/holding-onto-my-humanity/>.
- Baggs, M. (2018a, May 3). Independence theater. *Cussin' and Discussin'*.
<https://cussinanddiscussin.wordpress.com/2018/05/03/independence-theater/>.
- Baggs, M. (2018b, May 3). Snake Words: Hiding the dystopia. *Cussin' and Discussin'*.
<https://cussinanddiscussin.wordpress.com/2018/05/03/snake-words-hiding-the-dystopia/>.
- Baggs, M. (2018c, May 3). Snake Words: Person-centered. *Cussin' and Discussin'*.
<https://cussinanddiscussin.wordpress.com/2018/05/03/snake-words-person-centered/>.
- Baggs, M. (2018d, May 4). How they talk about us in private versus public. *Cussin' and Discussin'*. <https://cussinanddiscussin.wordpress.com/2018/05/04/how-they-talk-about-us-in-private-versus-public/>.
- Baggs, M. (2018e, May 4). Nice Lady Therapists and their war against human emotion: class, disability, and culture. *Cussin' and Discussin'*.

<https://cussinanddiscussin.wordpress.com/2018/05/04/nice-lady-therapists-and-their-war-against-human-emotion-class-disability-and-culture/>.

Baggs, M. (2018f, May 4). They don't even pretend about due process. *Cussin' and Discussin'*. <https://cussinanddiscussin.wordpress.com/2018/05/04/they-dont-even-pretend-about-due-process/>.

Baggs, M. (2018g, May 5). The problem isn't that we need institutions back. The problem is we haven't got as far away from them as we think we have. *Cussin' and Discussin'*. <https://cussinanddiscussin.wordpress.com/2018/05/05/the-problem-isnt-that-we-need-institutions-back-the-problem-is-we-havent-got-as-far-away-from-them-as-we-think-we-have/>.

Baggs, M. (2018h, May 9). Good agencies make people better, bad agencies make people worse. *Cussin' and Discussin'*. <https://cussinanddiscussin.wordpress.com/2019/05/09/good-agencies-make-people-better-bad-agencies-make-people-worse/>.

Baggs, M. (2018i, May 12). Developmental disability service agencies: Can't vs. won't. *Cussin' and Discussin'*. <https://cussinanddiscussin.wordpress.com/2018/05/12/developmental-disability-service-agencies-cant-vs-wont/>.

Baggs, M. (2018j, June 5). Why I'd sometimes feel safer dying on a street corner than going to the hospital. *Cussin' and Discussin'*. <https://cussinanddiscussin.wordpress.com/2018/06/05/why-id-sometimes-feel-safer-dying-on-a-street-corner-than-going-to-the-hospital/>.

Baggs, M. (2018k, June 12). The other kind of memory. *Cussin' and Discussin'*. <https://cussinanddiscussin.wordpress.com/2018/06/12/the-other-kind-of-memory/>.

- Baggs, M. (2018l, August 12). Who am I when I can't do...? *Cussin' and Discussin'*.
<https://cussinanddiscussin.wordpress.com/2018/08/12/who-am-i-when-i-cant-do/>.
- Baggs, M. (2018m, August 20). Let's get one thing straight. *Cussin' and Discussin'*.
<https://cussinanddiscussin.wordpress.com/2018/08/20/lets-get-one-thing-straight/>.
- Baggs, M. (2020, March 27). I don't just have one developmental disability. *Cussin' and Discussin'*. <https://cussinanddiscussin.wordpress.com/2020/03/27/i-dont-just-have-one-developmental-disability/>.
- Ben-Moshe, L. (2013). The institution yet to come': Analyzing incarceration through a disability lens. In L. J. Davis (Ed.), *The Disability Studies Reader* (4th ed.), (pp. 132-145).
- Brown, L. (2013, April 25). Medical discrimination: Handicapped left for dead. *The Georgetown Voice*. <https://georgetownvoice.com/2013/04/25/medical-discrimination-handicapped-left-for-dead/>.
- Cavar, S. & Baril, A. (2021). Blogging to counter epistemic injustice: Trans disabled digital micro-resistance. *Disability Studies Quarterly* 41(2).
- Cavar, S. (2021). Xenogenders, neopronouns, and the transMad toolbox. *Queer Disability Studies Network*. <https://queerdisabilitystudies.wordpress.com/xenogenders-neopronouns-and-the-transmad-toolbox/>.
- Denome, D. (2020, June 14). How do you symbolize intimacy? For many AAC programs, not particularly well. *mumblings from an autistic fairy*.
<https://donnie.lgbt/2020/06/14/how-do-you-symbolize-intimacy-for-many-aac-programs-not-particularly-well/>.

- Drake, S. (2013a, April 2). Updates on Amanda Baggs – surgery is on for today! *Not Dead Yet*. <http://notdeadyet.org/2013/04/updates-on-amanda-baggs-surgery-is-on-for-today.html>.
- Drake, S. (2013b, April 6). More updates on Amanda Baggs and links to other bloggers. *Not Dead Yet*. <https://notdeadyet.org/2013/04/more-updates-on-amanda-baggs-and-links-to-other-bloggers.html>.
- Ekins, E. [@queerlyautistic] (2021, July 10.) *If it wasn't for social media, I wouldn't have my longest standing friends*. [Tweet]. Twitter.
<https://twitter.com/QueerlyAutistic/status/1413953781419626500?s=20>.
- Erevelles, N. (2011). “Coming out crip” in inclusive education. *Teachers College Record* 133(10), 2155-2185.
- Foucault, M. (1988). *Madness and civilization: A history of insanity in the age of reason* (Richard Howard, Trans.) Vintage (Original work published 1965).
- Fricker, M. (2011). *Epistemic injustice: Power and the ethics of knowing*. Oxford University Press.
- Goffman, E. (1968). *Asylums*. Penguin.
- Gong, N. (2017). “That proves you mad, because you know it not”: impaired insight and the dilemma of governing psychiatric patients as legal subjects. *Theory and Society* 46, 201–228. <https://doi.org/10.1007/s11186-017-9288-0>.
- Hingsburger, D. (n.d). Burritos and cherry pies: Saying yes, saying no: What direct support professionals need to think about. *The Direct Support Workers Newsletter* 2(7).
https://www.vitacls.org/wp-content/uploads/2019/09/volume_2_7.pdf.

- Jackson, S. J., Bailey, M., & Foucault Welles, B. (2018). #GirlsLikeUs: Trans advocacy and community building online. *New Media & Society*, 20(5), 1868-1888.
- Jellicoe, J. (2021). *Sideways-glancing, we see: a reflection on the work of Mel Baggs*. Self-published.
- Jenzen, O. (2017). Trans youth and social media: Moving between counterpublics and the wider web. *Gender, Place & Culture*, 24(11), 1626-1641.
- Johnson, M. L., & McRuer, R. (2014). Cripistemologies: Introduction. *Journal of Literary & Cultural Disability Studies*, 8(3), 245–256. <https://doi.org/10.3828/jlcds.2014.21>
- Kinloch, V., Penn, C., & Burkhard, T. (2020). Black Lives Matter: Storying, identities, and counternarratives. *Journal of Literacy Research*, 52(4), 382-405.
- Leighton, E. [@esther_leighton]. (2021, July 22). *Words for things that many or all humans do but which are only used about disabled people. I'll start. "Toileting"* [Tweet]. Twitter. https://twitter.com/Esther_Leighton/status/1418310957969850370.
- Meekosha, H. and Shuttleworth, R. (2009). What's so 'critical' about Critical Disability Studies? *Australian Journal of Human Rights* 15(1): 47–75. <https://doi.org/10.1080/1323238X.2009.11910861>.
- Mitchell, D. T., and Snyder, S. L. (2018). *The biopolitics of disability: Neoliberalism, ablenationalism, and peripheral embodiment*. University of Michigan Press.
- Montgomery, C. (2001). Critic of the dawn. *Ragged Edge Online* (2). <http://www.raggededgemagazine.com/0501/0501cov.htm>.

Peters, G. [@mssineomine]. (2021, July 31). *Also if you all had listened to crips about how to handle this pandemic there'd be a lot less dead people and people who got sick* [Tweet]. Twitter. <https://twitter.com/mssinenomine/status/1421577275623952384>.

Peters, G. [@mssineomine]. (2020, June 28). *I checked and no one has ever actually done this hashtag. I want to add some. Please join in if you think of any #DisabledPeopleToldYou* [Tweet]. Twitter. <https://twitter.com/mssinenomine/status/1277285161290219520?s=20>.

Piepzna-Samarasinha, L. L. (2019). *Care work: Dreaming disability justice*. Arsenal Pulp Press.

Piepzna-Samarasinha, L. L. (2017, May). Crip infinity. *ANMLY* (25). <https://anmly.org/ap25/leah-lakshmi-piepzna-samarasinha/>.


Price, M. (2011). *Mad at school: Rhetorics of mental disability and academic life*. University of Michigan Press.

Regan, R. (2014, Aug. 6). Nice Lady Therapists. *Real Social Skills*. <https://realsocialskills.org/2014/08/06/nice-lady-therapists-2/>.

Robles-Anderson, E. and Appadurai, A. (2020). Editors' letter: Afterlives. *Public Culture* 32 (3 (92)), 449–452. <https://doi.org/10.1215/08992363-8358727>

Sins Invalid. (2015, Sept. 17). 10 Principles of Disability Justice. *Sins Invalid*. <https://www.sinsinvalid.org/blog/10-principles-of-disability-justice>.

Yergeau, R. (2018). *Authoring autism: On rhetoric and neurological queerness*. Duke University Press.

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