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## Critical Autism Studies Beyond Academia: An Annotated List

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## Critical Autism Studies Beyond Academia: An Annotated List

### Cover Page Footnote

I would like to thank everyone doing this work in practical ways, whether or not it is listed here and whether or not it uses academic language. I believe critical autism studies is at its best when it acts as an academic wing to back up the activists and advocates.

# Critical Autism Studies Beyond Academia: An Annotated List

Alyssa Hillary Zisk

Critical autism studies, or CAS, along with broader critical neurodiversity studies, draws on critical disability studies. These areas of study all unsettle the nature of their focuses: examining the social construction of autism, of neurodivergence, of disability. This has often been, and continues to be, an activist endeavor with activist-academics taking part (Woods et al., 2018). By the definition of what CAS is, its texts (considered broadly—not all are, in fact, text-based) and its thinkers are not limited to academic texts or thinkers. Consider Woods and colleagues' (2018) use of Waltz's (2014) definition of CAS:

The 'criticality' comes from investigating power dynamics that operate in Discourses around autism, questioning deficit-based definitions of autism, and being willing to consider the ways in which biology and culture intersect to produce 'disability.' (p. 1337)

Disability activists in general, and autistic activists associated with the neurodiversity movement and/or paradigm specifically, do these things whether or not we are also academics. We do this in blogs (Zisk, 2023a), in original fiction (Nelson, 2022), in fanfiction (Zisk, 2023b), in videos (Angulo, Chan, & DeThorne, 2019), and in non-linguistic communication that professionals pathologize as challenging behaviors (Asasumasu, 2011a; Baggs, 2005). As a reminder of this fact, I present an always-incomplete annotated list of some sources from beyond academia which:

1. Take defining actions of critical autism or neurodiversity studies,
2. Were not published in an academic journal, by an academic press, or as an academic thesis,
3. Have at least one creator who, as far as I know, doesn't have a terminal degree and is not employed as university faculty. This is to ensure the list includes people who are fully outside/beyond academia,

rather than primarily highlighting the many people who do important work both inside and outside of academia. (Note: pieces where some co-creators have terminal degrees or where the creator is enrolled in graduate school at the time of compilation are occasionally included in cases where additional marginalized identities are involved.)

The following list features select works that meet these criteria. For the sake of readability, URLs are included in the concluding references.

**Administration for Community Living. “All of Us Are People All of the Time”: An Autistic Self-Advocate’s Perspective.**

This article by the Administration for Community Living profiles Pervez, a trans, Muslim, multiply disabled educator, community organizer, public speaker and internet researcher. Pervez urges people to ask “why” about the way things are—including around autistic representation and the framing of autism. The additional barriers he discusses for multiply marginalized autistic people are key to the interplay between culture and biology in the creation and reinforcement of disability. Given the deficits of common autism definitions and discourse—note that Lovaas, pioneer of ABA, directly said autistic people were not people in the psychological sense (Chance, 1974)—the title also challenges the deficit framing of autism.

**Asasumasu, K. [Neurodivergent K]. “What Would Meeting You Halfway Be?”**

Asasumasu (she/they) is a biracial multiply neurodivergent activist and the coiner of the term “neurodivergent” (not neurodiversity). This post discusses the power dynamics in discourses and interaction around autism. They point out that all communication problems have multiple sides, which calls our presumed communication deficits into question, and notes that “meeting us halfway just isn’t done.” This post goes well with the “Double Empathy Problem” (Milton, 2012) and with recent results showing that autistic-autistic communication is effective (Crompton et al., 2020). The problem really is in the interface, not the individual, as Asasumasu suggests logically must be the case.

**Asasumasu, K. [sherlocksflataffect]. “PSA from the Actual Coiner of ‘Neurodivergent.’”**

Asasumasu (she/they) reminds people of the actual definition of the term, noting that neurodivergent is “specifically a tool of inclusion.” She lists some

of her own neurodivergences, several of which people regularly argue fall outside the realm of neurodivergence or neurodiversity: “Autistic, epileptic, have PTSD, have cluster headaches, have a chiari malformation.” This reminder is particularly critical as academic neurodiversity work has an unfortunate tendency to limit what they consider as neurodiversity, such as by using Shah and colleagues’ (2022) definitions of terms rather than Asasumasu’s.

### **Autball.**

Autball is comic created by an anonymous autistic parent. It presents a wide variety of neurodivergent advocacy topics in accessible ways, including concepts key to CAS. One strip, “Autistic Advocacy,” discusses the layers of power and invalidation used to ensure no autistic person need be listened to by parents or experts who prefer not to listen. “Aupposite Day” strips show the effect of culture in creating disability by showing how neurotypicals could be disabled in a culture that considered (certain) autistic tendencies to be the correct way to do things. “NT vs ND” comics have a similar effect, and they additionally challenge deficit framings by showing the problem lies at least as much in a mismatch as in either side being incorrect.

### **#AutChat.**

#AutChat is a twitter hashtag-based chat which has run since February 2015, by and for autistic and similarly neurodivergent people. Each meeting of the chat (4-5pm EST every Sunday) focuses on a particular topic. The moderators begin with an introduction to what #AutChat is and a ‘question zero’ asking participants to introduce themselves and/or their interest in the day’s topic. Topic-specific questions and discussion follow. Critical topics have included Autistic cultures and communities, which dominant discourses may presume to be an oxymoron; language preferences, which are directly relevant to how we discuss autism; representation; and autism research itself.

### **Autism Positivity Day Flash Blog.**

This blog ran for four years, initially inspired by someone who found a blog after googling “I Wish I Didn’t Have Asperger’s” and running again with different themes in the following years. In 2013, the theme was 1000 Ausome Things, in 2014 it was Expressions of Posautivity, and in 2015 it was Acceptance, Love, and Self-Care. These themes all challenge deficit-based

assumptions about autism, and many submissions address power dynamics and cultural forces involved in discourse and the construction of disability.

### **Autistic Archive.**

The purpose of the autistic archive is to preserve information about the autistic community and neurodiversity movement, including its history. Its resources include a timeline covering the 1990s to the present day, with the last entry for an event in April 2022. It points to books, blogs, and people associated with the movement as well. A significant portion of the work listed individually on this list is referenced, directly or indirectly (e.g. by profiling an author) on this archive. Compiling this history as worth knowing is itself a challenge to whose knowledge and writing matters, part of the power dynamics in autism discourses. A significant portion of the resources linked from the site individually challenge power dynamics or deficit based framings as well as discussing the effects of culture in producing disability.

### **Autistics.org.**

Many of the articles on the archived Autism Information Library page take key actions of CAS: “Don’t Mourn for Us” is reprinted here and may have become the canonical example, but “Inertia: From Theory to Praxis” addresses how the (culturally situated) structure of activities interacts with inertia in creating disability, and a great many articles in the “The Autistic Perspective” section challenge deficit framings of autism, power relations in autism framings, or both. “Autism, Speech, and Assistive Technology” challenges power, expertise, and what success and barriers look like. This site was last updated June 11, 2011 to convert it into an archive, and even this archive is now available only on the Internet Archive’s Wayback Machine.

### **Baggs, M. Don’t Ever Assume Autism Researchers Know What They’re Doing.**

Baggs is a multiply disabled person involved in a variety of disability communities, including autistic ones. Sie were most at home in the developmental disability self-advocacy community, and much of their neurodiversity-relevant work drew from developmental disability self-advocacy movements. This article broadly criticizes autism research, complaining that “The state of autism research is pretty uniformly terrible.” Sie then goes on to discuss assumptions, including deficit-based assumptions, contained within Simon Baron-Cohen’s “Reading the mind

in the eyes” test, the power dynamics around these assumptions, and the problems that can result from these assumptions in meaning. Most of this post discusses a particular example of poor-quality autism research, but Baggs notes that (and how) many of the assumptions and problems generalize to other contexts. Sie also gives some space to linguistic problems inherent in the notorious Sally-Anne test.

### **Baggs, M. Reviving the Concept of Cousins.**

Baggs discusses movement history. Sie explains the concept of autistic “cousins,” who (probably) aren’t autistic themselves but are similar in important ways. The term “autistic cousin” is older than the term “neurodivergent,” but “autistic or similarly neurodivergent” is currently used alongside “autistic people and autistic cousins” with similar meaning. Autistic cousin is a sociological term, not a clinical one, and is not aligned with any particular diagnosis. The explicitly sociological nature of the term highlights the social factors involved in the construction of specific disability labels. Critical work which would benefit from a concept like the broader autism phenotype without the pathologizing and possibly surrounding other forms of neurodivergence would do well to consider the “cousin” for this purpose.

### **Bartmess, E. Writing Autistic Characters: Behaviorizing vs. Humanizing Approaches.**

Bartmess challenges the behaviorizing (behaviorist) construction of autism as it exists in fiction. Bartmess not only examines how behaviorizing descriptions dehumanize and reinforce the perception of the autistic subject as “other,” but gives guidance on how to do it differently.

### **Becker, C. & Bjørnstad, K. (Eds.). Autistics Speaking Day.**

Corina Becker proposed what became Autistics Speaking Day in response to a Communication Shutdown event for autism awareness. The Communication Shutdown meant to have people shut off all social media and internet communication for the day to represent the isolation the organizers considered inherent to autism. However, Autistics Speaking Day challenged this on a variety of levels, including the observation that many autistic people actually use the internet to reduce their isolation. The goal of Autistics Speaking Day was to “flood every social networking site we know with our accounts, our experiences, what it feels like to Autistic” (Becker,

2010). The suggested experiences—and the experiences participants actually discussed—absolutely address power dynamics and question common understandings of what autism and disability are, both implicitly and explicitly. The number of participants has decreased since the original 2010 event, and Becker indicated that November 1, 2023 would be the last run of the event, but the blog will remain online.

### **Ben-Oni. NeuroCrit: An Expansion of Critical Race Theory.**

Ben-Oni explains Critical Race Theory (CRT) and argues for the inclusion of melanated people in order to ensure justice for them. Ben-Oni then defines NeuroCrit, situating it in the genealogy of CRT alongside other additions or expansions of the theory: “NeuroCrit addresses the social construct of neurotypicality by examining the ideology of ableism and its intersection with racism within the neurodiversity paradigm” (2021).

### **Çevik, K. How My Nonspeaking Autistic Son Taught Me YouTube Speak.**

Çevik is a speaking parent of a nonspeaking autistic son. She challenges language deficit assumptions by discussing the linguistic innovation of her son’s Youtube speak, despite medical claims that he cannot communicate beyond the level of an infant. She argues for presuming competence and challenges ‘expert’ assumptions of what autistic people cannot do. And then she discusses how the very interventions she is told to use would have eliminated the way her son successfully communicates. Cultural discourses and assumptions about autistic deficits enforce disability unless we can prevent them from doing so.

### **Chavisory. Autistic Social Experience and the Sally-Anne Test: Stop Jerking Little Kids Around.**

Autistic criticisms of theory of mind as a theory of autism are plentiful. Chavisory provides another new and critical criticism of the notorious Sally-Anne test regarding differences between autistic and disabled children as compared to non-disabled adults: “Things happen to us that do not happen to them, and those patterns of experience impact our predictions about social situations” (2023). She then explains why this matters: autistic children are taught to distrust their instincts, often learning that if something looks too easy, then it is a trap. They also learn that other people know and understand things they we don’t know—not the other way around. Learning that we should not expect to deceive a peer successfully requires what the



researchers say theory of mind is—but it also teaches us to respond to the Sally-Anne test in ways the same researchers would code as “incorrect.” Chavisory challenges the typical theory of mind tests by pointing out these tests must discard differences in life experience between autistic children and non-disabled adults. In doing so, she challenges a commonly presumed deficit and points out the cultural component in its ‘evidence’ base.

### **Disability Visibility Project. Interview with Co-editors of *Sincerely, Your Autistic Child*.**

*Sincerely, Your Autistic Child*, (Eds. Ballou, daVanport, and Onaiwu, 2021), is a book-length compilation of essays addressing autism-related topics, including intersectional identities, community, acceptance, and challenges to common autism discourse. Contributors question who gets diagnosed, who does not, and who these patterns serve.. The interview with the editors includes discussion of representation: this includes both the wider range of gender and sexuality experiences than professionals typically address and the need for having autistic editors editing autistic writers. Power is explicitly part of this, mitigating differentials between writers and publishers by contextualizing autistic writing. Finally, power and ableism in autism discourses and action, both around publishing and around autism month, close out the interview.

### **enderver\*. Unaccounted For: Impairments, Disabilities, and the Social Model. *Homo Qui Vixit*.**

Despite the title, this is in fact a rejection of the medical model. endever\* discusses the social model and how it does not fully address all of their symptoms. Xe gives examples of how some aspects of their experience, including autistic aspects, may not be fully accommodated even in a redesigned anti-ableist society—and explains why, despite this, the medical model is not the answer to these missing pieces. endever\* also addresses the power imbalances in hir desire to “retain the power to name and describe the ways I suffer, not leave the delineation up to the cisnormative, heteropatriarchal, racist, sizeist, ableist field of medicine” (2019), addressing the combination of biology and culture in noting the dynamic connections between inaccessibility and impairments located within themselves. In criticizing the way the medical model makes moral judgments about symptoms which may, in and of themselves, be distressing, endever\* challenges this model in favor of something we have not yet found.

**Jackson, L., Haagaard, A., and Williams, R. Disability Dongle. Platypus: The Castac Blog.**

The “Disability Dongle” is about epistemic injustice. The authors share Jackson’s definition of a disability dongle—“a well intended elegant, yes useless solution to a problem we never knew we had.” They describe the power relations and epistemic injustice that leaves disabled experts who criticize these technologies in comment sections instead of the main stories. They further describe the power relations in what happens when we complain. The authors argue that creating a disability dongle is, in fact, producing an idea of what disability is—precisely what critical disability studies in general and CAS in particular must challenge. This article is not autism-specific, but it is critical, and it does cover autism. One example of a disability dongle, for example, is the use of Google Glass to teach autistic children to make eye contact and recognize emotions.

**Montgomery, C. The Imposition of Administrative Control Gets on My Nerves.**

Montgomery discusses the loss of control and power that people with disabilities can suffer in settings meant to address actual needs, such as assistance with toileting or bathing. However, the return of control with smaller or differently located settings can only occur if control was not the purpose or the perceived need. This is key to Montgomery’s argument, as the self-advocacy movement and the neurodiversity movement alike have been full of discussions of control, in cases where geography may not serve as a proxy because control was the purpose and not a by-product of logistics. Montgomery addresses the perception of some people’s primary disability-related need as being control and how it affects institutionalized disability experiences, with or without an institutional building.

**Montgomery, C. On the Limits Tacitly Imposed By Communication Systems.**

Montgomery challenges full-time fluent speakers. It begins with thinking of up to 128 important words, phrases, or sentences you may want to communicate. It moves on to grappling with power, the limitations of assistive technology, mistaking those limitations for deficits in people, and how power and the limitations of communication systems combine to produce (more) disability. This is not autism-specific. However, many autistic people face these limitations in their communication. As autistic people who

use or lack access to communication systems Montgomery's challenge most directly relates to are severely underrepresented in autistic discourse and spoken for rather than getting to speak for themselves in broader autism discourse, this is important in critical autism work.

**morse, m. A Critical History of the DSM.**

The critical history of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM) provided addresses the power dynamics and deficit-based assumptions that, as morse notes, has been involved in maintaining social order for its entire existence. Autism is given as an example within this critical history, and the critical history applies to autism along with all other diagnoses in the DSM.

**Politeyeti. Revised Alternative Autism Criteria.**

Politeyeti's alternative criteria challenge the deficit-based DSM-IV (-TR) definition of autism by specifying reduced awareness or use of non-autistic nonverbal communication rather than nonverbal communication. Politeyeti also addresses the combination of culture and biology in constructing disability by explicitly specifying that the distress or impairment may be a result of the social response to these traits rather than purely due to the traits themselves. These alternative criteria may be better considered as a non-exhaustive list of partially reframed traits, as they are primarily based on Politeyeti and their closer contacts, but they nevertheless constitute critical reframing. Note that researchers who want to make use of the criteria or some portion of them should contact the author.

**Real Social Skills. Meaningful Echolalia.**

Real Social Skills addresses the role of culture in producing disability by discussing how many people, including people without disabilities, use repeated phrases and references in their communication. This discussion includes commonly accepted literary examples of this, then proceeds to discuss the ways this same acceptance and attempt at understanding the underlying meaning is often not given when the person using a reference or repeated phrase is considered to have a disability. Real Social Skills also notes that just as people without disabilities have the right to use references to communicate, people with disabilities also have this right—that is, they have the right to keep using echolalia to communicate. While the role of echolalia in language development is gaining attention and acceptance under the

terminology of gestalt language processing and natural language acquisition, the right of autistic people to continue communicating in this way and to be understood while doing so is less often addressed.

**Shi, Jane. Reimagining the Autistic Mother Tongue.**

Shi addresses the deficit framing that autistic people face whether or not we (or those around us) are aware that we are in fact autistic. She also addresses power in both the discourse and the practices around language, around adoption, around autism and race combined. As part of this, Shi discusses the ableist name of autism in Chinese, what would be a better name, and how colonialism has impacted the language. She includes her somewhat joking and playful proposal of a different name, with the meaning “those who allow themselves to love themselves,” and invites us to consider the name(s) for autism in our languages.

**Sterling, S. [@artistAuDH]. The more I consider my theater training . . .**

In this Twitter thread, Sterling discusses embodiment and how the teaching of masking and “social skills” appears unnatural because it is analogous to initial read-throughs of plays with blocking (directed motion on/ across the stage). Sterling explains how our connection to our bodies is systematically broken down by a culture that fails to recognize what it is truly uncomfortable.

**This is Autism Flash Blog.**

This flash blog has over 200 posts (245 if every post made on November 18, 2013 was in fact a flash blog submission) all in some way challenging what autism is, in response to pathologizing discourse about autism from the non-profit organization Autism Speaks.

**Tilton, Saorise. Eye Gaze Access for Autistics.**

This is a presentation about eye gaze AAC [tools to support people who cannot always use speech to communicate] access for autistic people. It is also a presentation about how cultural assumptions around disability needs produce (more) disability and a presentation challenging common assumptions about what the ‘deficits’ of autism really are. Tilton notes that AAC people control with eye gaze is typically considered for people whose disabilities are recognized as primarily motor disabilities. Tilton argues that autism does involve a motor disability, and that the difficulty in getting eye

gaze for autistic people is itself a barrier. It's about the power issues with insurance that generally does not consider autistic people as candidates for eye gaze access.

### **TuttleTurtle. My Mask is Pain, not Neurotypicality.**

Masking, camouflage, and passing have been getting more attention in autism discourse, driven by critical work by autistic advocates and activist-scholars. While the theory does not inherently specify that this masking is to pass as neurotypical, most examples work that way. Tuttle discusses both this tendency and an alternative which seems more like intentionally taking advantage of diagnostic overshadowing as a form of masking—here, their mask is chronic migraine.

### **[Vranzian], Sam. & endeaver\*. Interviewing Saoirse.**

Two AAC users, one autistic, interview a third Sam and endeaver\* interview Saoirse about AAC. Explicit discussion of Saoirse introducing endeaver\* to AAC challenges the (also discussed) professional gatekeeping and power dynamics around AAC specifically and communication more generally in autism discourse and practice. In discussing AAC and multilingualism, specifically around Irish, Saoirse also gets into culture, access, and disability. In this interview, Saoirse also imagines what a communication accessible world would look like, examining how this change in culture would change a great many things around disability experiences and challenging the power dynamics of gatekeeping around communication access for everyone, not only around autism.

## **Conclusion**

This list can never be complete. Even if the time and space were taken to complete it at a particular instant, it would be out of date: people are still taking the actions of CAS studies outside academia. However, it contains a variety of examples of challenging deficit-based definitions and assumptions around autism; calling out power dynamics in discourse and action alike; and pointing out the ways power, assumptions, and society at large produce and exacerbate disability. Your topic of interest might not be represented on this list, but there almost certainly is critical work on it happening outside of academia. This is some of the work I am aware of through my community connections, and I encourage critical autism scholars to be connected

enough to Autistic communities to learn about and ethically engage with work in their areas, both outside academia and beyond this list. Even for a list like this, ask yourself: who is missing?

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