Toward a Culture of Access:
Lessons from the Neurodiversity Movement

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I'm so excited to be here and to talk with all of you today. Before I begin my talk, I'd like to attend to access and the space in which we currently dwell. First, please come to this room and use it as you need to. Feel free to exit, re-enter, move, shift, or roll around on the floor. Second, I have several access copies of my talk, both in large and regular-size font. I might ad lib or skip over certain parts occasionally, but the script represents a close approximation of what I'll be saying. As well, I am hoping we might have time for conversation afterward, and there are post-its going around in case you'd like to jot down notes or questions that you'd like to pass up front or save for a later time.

In order to generate discussion, I've structured my talk more as a series of questions, problems, and stories than I have a series of pronouncements or arguments. It's not that I'm not arguing things — it's more that I want us to linger on the stories that our graduate curricula tell about disability. The title of my talk, "Toward a Culture of Access: Lessons from the Neurodiversity Movement," borrows from Elizabeth Brewer's work on mental disability and and our collaborative work on the design of campus spaces. A culture of access, she notes, is a culture of participation and redesign (Brewer, Selfe, & Yergeau, 2014). Admittedly, I am about to linger primarily on problems endemic to the very design and conceptualization of graduate education, on the ways in which graduate programs promote ideologies of hyper-ability. But I linger on the badness, as it were, because in order to *redesign* or *transform* our curricula, in order to foster a culture of access, we need first to recognize that disability is not the problem. Rather, we are.

In today's talk, I am hoping that we might unpack a few of the many themes that attend disability and graduate curricula, using these themes as jumping off points

for potential action, for potential places to start in making graduate school a more hospitable space for disabled students. These themes, as I'm identifying them, include threat, rigor, and recruitment.

>> **somnolence**

When the Americans with Disabilities Act passed in 1990, non-disabled people started panicking. Journalists claimed that the ADA offered a "lifelong buffet of perks, special breaks and procedural protections" for people with "questionable disabilities" (Shalit, as cited in Colker, 2005, pp. 5-6). Politicians complained that the ADA was an invitation for an "avalanche of frivolous lawsuits" (Colker, p. 7). Celebrities also joined the panic wagon. At one point, Penn and Teller (in)famously claimed that the ADA "coddled" disabled people [because goodness knows that when we think about ramps and Braille signage, we instantly think about coddling].

Higher ed was not exempt from ADA outcry. Faculty and administrators complained that so-called *reasonable accommodations* would only enable lazy students and fakers to game the system and lessen the rigor of a college education. Perhaps one of the more iconic stories of ADA backlash is that of Somnolent Samantha. In 1995, then-provost of Boston University Jon Westling severely restricted accommodations for learning disabled students: among other moves, he forbade the disability services office from approving accommodation requests and instead moved all authority to his office. During the course of the school year, Westling delivered a series of talks that warned of the "excesses" of accommodation. As one example, he described Somnolent Samantha, a student in one of his classes who, because of her supposed learning disability, required accommodations. With disdain, Westling noted:

> The letter explained that Samantha had a learning disability "in the area of auditory processing" and would need the following accommodations: "time and one-half on all quizzes, tests, and examinations;" double-time on any

mid-term or final examination; examinations in a room separate from other students; copies of my lecture notes; and a seat at the front of the class. Samantha, I was also informed, might fall asleep in my class, and I should be particularly concerned to fill her in on any material she missed while dozing. (Blanck, 1998, p. 3).

Notably, Westling later revealed that Samantha was a fiction: he completely made her up. When several students sued BU over disability discrimination, the court ruled in their favor in 1997 in large part because Westling's Samantha stories "expressed certain biases … about learning disabled students" (Guckenberger et al. v. Boston University). After losing the lawsuit, Westling continued lambasting the ADA and disabled students, claiming, among other things, that Somnolent Samantha "symbolized real learning disabled students," that "learning disabled students are victims of overblown and unscientific claims by … disability advocates," and that "Universities have acceded to demands from extremists to exempt students from a growing range of academic requirements."

>> threat

It is now 2019, and yet these remain familiar arguments. Despite accommodating its graduate students, the academy still by and large operates under a cost-burden model when considering disability. The ADA's very appeal to reasonability — and what constitutes a reasonable accommodation — upholds the notion that institutions unto themselves need not transform into more accessible spaces... *because accessibility will threaten the institution*. This morning I am concerned with a disability threat of a particular kind — that of neurodivergence. Shorthand for *neurological divergence*, the term neurodivergence refers to anyone whose headspace (neurology, cognition, learning, attention, psychology, communication, or cerebral signals) diverge from the norm. In other words, it is a way of describing disabled people who have disabilities that in some way involve the brain (though I might argue that neurodivergence is even more expansive than mental disability, in that divisions between body and mind are faulty and elide a whole host of

experiences). More than this, though, neurodiversity as a movement is a concerted push against what Nick Walker has called the pathology paradigm. Far from regarding disability as a tragedy or a deficit, the neurodiversity movement understands disabled people as minoritized and marginalized subjects, as people deserving of rights and justice (see Brown; Çevik). It is an orientation to the world that welcomes and waves toward difference, rather than merely, barely, or begrudgingly tolerating it.

But because neurodiversity welcomes neurological difference, it is also a threat. What room is there for neurodivergence in the academy, in spaces that valorize intellect and a so-called "life of the mind"? In her interviews with disabled academics, Katie Rose Guest Pryal (2017) relates how this "life of the mind" sentiment serves as an oppressive macrostructure in university settings: "in academia," one of Pryal's interviewees notes, "one's brain is supposed to be the most essential asset one has" (p. 8).

Impaired brains make for impaired scholarship and teaching — or so goes the common logic of the academy. Even well-meaning campus initiatives on mental health, wellness, and resilience can reinforce this logic: Healthy brains yield healthy work. Resilience is valued because it is typically conceived as an individual property rather than a function of institutional conditions. As Erika Strandjord (2018) notes, lack of resilience if often claimed as a root cause of student suffering; resilience and its attending metaphors (such as *grit* and *coddling*) "diagnose students as deficient and not belonging in academia." In this regard, neurodivergence threatens time-to-degree, interpersonal relations, rational discussion, and professional development. Disability functions discursively as both a cost and a threat. Take, for instance, the following description of the Autism Special Interest Group for AHEAD, the Association of Higher Education and Disability: "The Autism/Aspergers Special Interest Group provides information and resources for professionals working with students with Autism. As this challenging population on college campuses continues to grow, the SIG will sponsor conference session and have a listserv to share ideas and resources."

While other AHEAD special interest groups focus on student needs, working toward equity and access, addressing salient issues that face students, improving campus climate, the autism group instead appeals to the challenges posed by neurodivergence. In other words, our focus is directed to misbehavior and disruption, not eliminating barriers or reinventing pedagogical structures. I might also suggest that this description is a subtle rhetorical versioning of the all-suffering professional. As represented here, the challenge isn't about transforming ableist spaces; the challenge, instead, is about academic staff coping with overbearing students.

Although changing the language of this description — or similar institutional descriptions that might appear on disability services or graduate school websites — won't wholesale change the realities disabled graduate students face, such revisionary actions could articulate more radical, just futures.

Threat manifests in every corner of graduate education. Outside of coursework, accommodation systems are rarely equipped to assist disabled students through programmatic milestones. Students with mental disabilities represent an especially vulnerable population in this regard because their accommodations typically clash against rigid institutional structures — and, indeed, many standard accommodations that accompany graduate students' diagnoses are not the supports they need in order to thrive in their programs. In 2014-15, for example, *Buzzfeed*, *Huffington Post*, and the *New Yorker* all ran pieces about mentally ill students who had been coerced into taking medical leaves and were forced out of their academic programs (typically following a depression diagnosis or suicidal ideation). Depression in these contexts is typically framed as a threat to all facets of grad studenthood, most especially those that concern writing and productivity. (One of my more surreal experiences as a faculty member was receiving a new faculty handbook from a colleague that painstakingly urged junior faculty to stop being depressed if they wanted tenure. As if it were a magic switch.) In these examples, mental illness rubs against the very fabric of graduate life: Students need to sit for exams by specific dates, defend prospectuses and theses and dissertations by specific dates, and time-based accommodations — which may be well suited for

coursework — are suddenly viewed as unreasonable in post-candidacy contexts. Neurodivergent students threaten retention and degree timeline averages.

To be clear, I am suggesting that neurodiversity is indeed a threat, but not in the manner that the examples from Somnolent Samantha or AHEAD might suggest. Rather than behold such threats as challenges to be overcome, what if we instead consider that the university itself must be threatened? In this I am summoning Erin Manning's (2018) work on neurodiversity as an antithesis to academic life. She writes: "What is it about the stimmy, ticcy, or spastic body that threatens neurotypicality? What is it about it that so readily reads as unintelligent, unknowing? ... We know that bodies get in the way of learning, of knowing, of speaking. Otherwise, why would we have to sit in chairs all day, stand still when we speak, and stop to pay attention? Is that why neurodiversity is so threatening to neurotypicality's certainty about what it means to know?" (p. 19).

Obviously, regardless of the positions we hold at our own institutions, we are constrained. We are constrained by legalities, bureaucracies, and finances. But these constraints need not always interfere with our radical imagining of neurodivergent futures, of neurodivergent threats. What would it mean to do away with time-to-degree completely? What would it mean to eliminate standardized testing? What would it mean, as has been posed in some of the CGS workshops thus far, to do away with dissertations and theses completely? In other words: Why do we cherish our darlings, and in what ways do these cherished darlings threaten our students?

>> rigor

Rigor is an organizing principle of academic life, a principle that neurodiversity threatens. In *Mad at School*, Margaret Price (2010) argues that commonplace beliefs in academia enforce idealized notions of able minds and bodies. Participation, presence, reason, and collegiality are but a few of the beliefs that Price analyzes. Following Price's lead, I might suggest that *rigor* is another such

belief that animates graduate programs in particular.

Take, for example, the following language, which is typical of many university offices: "the university is committed to ensuring that graduate students receive appropriate and reasonable accommodations." In this statement, emphasis is placed on appropriateness and reasonableness; there is an implication that students might otherwise ask for too much, or receive accommodations for which they are not entitled. In other words, we do not want to make graduate school easy for anyone, least of all disabled students.

I would argue that these subtle appeals to rigor manifest in ETS's materials on "Disabilities and Health-related Needs" for the GRE. Under the heading "Things to Keep in Mind When Requesting Accommodations," ETS notes that "Accommodations on high-stakes tests are designed to permit equal access to the test, not to achieve an outcome such as finishing the test or performing your best." There are many possible interpretations of this passage. One is that ETS is appealing to the Americans with Disabilities Act Amendments Act (ADAAA), and its decision to grant accommodations is based on thresholds for reasonableness and legal compliance. But we might also note how the phrase "equal access" in this context is positioned distinctly against *finishing the test* and *performing your best*. Arguably, ETS is mirroring the logics of graduate admission writ large: We are so consumed with getting students *in* that we fail to support them once they're here. There are doorways to the building, but no support beams for the building's structure. Any understanding of access as mere entry is an unjust formulation of access; it is a version of access that positions rigor and challenge above student livelihood. This, I suggest, is an access that crushes.

Stepping back from ETS's access rhetoric, we might want to consider the guiding logic of the term accommodation unto itself. To accommodate is to "make fit," to "hold without crowding or inconvenience," to "give consideration to" (Merriam-Webster). In other words, accommodation is another instantiation of so-called equal access: accommodation makes no promises for neurodivergent students because its goal is to uphold the structures that excluded them to begin

with. While one interpretation of ETS's formulation of access is to lobby for better student accommodations, such advocacy assumes that the GRE is a just measure for determining futures. Accommodating, in this regard, involves making disabled students fit, so long as their fitness does not inconvenience or defile the very components that make the GRE the GRE. In fact, arguably the GRE and other such standardized tests are themselves mechanisms for determining, diagnosing, and detecting disability, asserting student scores as a predictor for future performance in a graduate program. In other words, the GRE doesn't merely accommodate disability; it creates it (along with an entire market of test prep materials designed to ameliorate the very barriers the GRE erects).

As disability studies scholar Jay Dolmage relates, accommodation unto itself is a form of segregatory design, wherein disabled students are slotted into classrooms and university life as afterthoughts (this, versus universities intentionally designing curricula and spaces that would be broadly accessible all the time). As Dolmage (2017) notes, "when the accommodations that students with disabilities have access to, over and over again, are intended to simply temporarily even the playing field for them in a single class or activity, it is clear that these retrofits are not designed for people to live and thrive with a disability, but rather to temporarily make the disability go away" (Ch. 2, n.p.).

Where Dolmage's research on accommodation is most important for our purposes, however, is his analytical work on the effects of Westling's Somnolent Samantha storying. Academic expectations, Dolmage notes, demand that students function as "Super Samantha," an "idealized character… [who] is invoked most often to show that universities do not have the educational resources, infrastructure, or pedagogical skill to accommodate her in the classroom" (Ch. 3, n.p.). What Dolmage notes here is particularly relevant to graduate education: think, for example, about the ideals espoused in promotional materials for PhD programs, or the ways in which this rhetoric of superness, intellectual superiority, and skill manages our approach to graduate admissions, funding decisions, and the design (and attainment) of programmatic milestones. In other words, Dolmage's "Super Samantha" is the ideal graduate student.

Slow Samantha, by contrast, is Dolmage's way of storying how institutions conceive of disabled students. As Dolmage aptly notes, "In the disability community, there is awareness that accommodations for students with disabilities have traditionally been cast as happening at the cost of all other students, and particularly at the cost of Super students." Per Dolmage, the figure of the slow student is a figure that foregrounds the neoliberal commitments of the university: Slowness is antithetical to rigor because graduate school valorizes speed in its approach to student learning; and slowness is antithetical to university funding structures because its pacing translates to added dollars.

Here I can offer a story from my own graduate student past as a case in point. While in graduate school, I requested teaching in a computer classroom as a disability accommodation. I eventually received this accommodation — but that eventuality was a fraught and hard-fought eventuality. Upon making this request, I became entwined in an email thread about my costs to the department (for computer classrooms cannot hold as many bodies as traditional classrooms can). My doctoral advisor was notified about my costliness, as were departmental staff. The thread repeatedly appealed to enrollment loss and used this loss to question whether I should be allowed to teach certain courses.

My story is not unusual. Indeed, graduate students occupy incredibly precarious positions given that many are both students and employees of the university. Rigor is among the primary beliefs of graduate discourse: Without rigor, we would not be speedy. Without rigor, we would not have research. Without rigor, would we even know ourselves as academics?

>> intentional recruitment

In the spirit of these questions, I now want to change my tone somewhat. We need critique, but we also need places to start building — concrete action items that allow us to deploy this critique, to undo and complicate and question those beliefs

that enforce ableism and promote able-mindedness and able-bodiedness as unquestioned ideals in graduate school.

In the field of disability studies, we often talk about universal design. UD is, in short, a design process that endeavors to include the maximum numbers of bodies possible. UD's histories are architectural, but its current trajectories are interdisciplinary, and are especially present in scholarship on pedagogy and education more broadly.

There have been some notable and important critiques of UD, many of them emerging from scholars in writing studies. Jay Dolmage (2009), for instance, has argued that "universal design has become a way to talk about changing space to accommodate the broadest range of users, yet consistently overlooks the importance of continued feedback from these users" (p. 172). Importantly, Dolmage (2015) observes that, pedagogically, UD often functions as little more than a series of checklists, items that instructors and programs can simply check off and then contentedly ignore. Recognizing that programs do indeed need places to start, Dolmage offers a series of practices that instructors and administrators can use as a means of retooling their classroom spaces (and he rather purposefully offers these practices in a [crowd-sourced, fully editable wiki](#)).

In this spirit, I offer some potential places to start, with the hope that these practices might jumpstart conversation. In offering these practices, I draw from scholarship in disability studies as well as my past work with autistic-led advocacy organizations such as the Autistic Self Advocacy Network (ASAN) and the Autism National Committee (AutCom). To be clear, these are not exhaustive suggestions, nor are they necessarily easy places to start. I hope, then, that these ideas enable us to think more complexly, pointedly, and actively about neurodiversity and graduate students.

1. Intentional recruitment & access advocacy

In university contexts, disability is typically framed as a negative or a series of deficits. In many ways, the negatives have been on full display throughout my talk thus far: Neurodivergence as a cost, a threat, an antithesis to rigor. Such rhetoric dehumanizes students and perpetuates stigma that correlates mental disability with lack of intellectual worth. As Margaret Price and Stephanie Kerschbaum note, "A campus culture that stigmatizes or simply ignores mental disability tends to encourage silence and non-disclosure, which further exacerbates other problems surrounding these disabilities" (p. 5). Given the risks that deficit frameworks impose, I'd argue that it is imperative to actively promote disability as "enabling," as a way of being in the world that yields critical insight (Brueggemann et al., 2002). In other words, building a culture of access requires a building of disability culture.

For instance, is disability a component of your graduate school's diversity, equity, and inclusion plan? If so, in what ways is disability described, addressed, positioned, or realized? Relatedly, what efforts do your graduate programs make to *recruit* graduate students with disabilities? Are your disabled graduate students mere accidents of arrival, or are they students you actively wanted (and solicited) on campus? What plans do you have to actively support such students, financially and otherwise, while they are here?

Intentional recruitment, however, cannot end once disabled students are here. Access advocacy is a collective responsibility; it should not be relegated to the disability services office. As Ruth Osorio notes, "Too often, disability advocates bear the burden of advocating for increased accessibility. But our calls for greater inclusion would be stronger and more persuasive if everyone joined in." In the 30-second video clip I'm about to share from *Composing Access*, a project of the CCCC Disability Committee in College Composition, Osorio describes access advocacy in the context of academic conferences and offers advice for how all attendees can move access into action.

[Show clip from Ruth Osorio's Access Advocate video, 1:43-2:08]

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Access advocacy need not simply be about conferences; indeed, the suggestions Osorio offers might extend to professional development as well as classroom spaces. The general idea is for each of us to take up the labor of access, to foreground disability in our maneuvers and encounters, to actively center disability in our daily work.

2. Leadership of those most impacted

This phrase hails from Patty Berne, co-founder of the disability performance group Sins Invalid, in her primer on disability justice. Many spaces that purport to be about disability actively exclude disabled people. Any conversation on program design and accessibility needs to meaningfully include those who will be most impacted by curricular decisions. In this regard, it's important not only to consult and genuinely listen to the concerns of disabled graduate students, but, following Berne, to also examine the ways in which disability and health are inextricably intertwined with constructions of race, class, gender, and sexuality. For example, disability and class frequently converge over considerations of diagnostic testing and associated costs. As well, women, nonbinary folks, and people of color are often tracked into some of the more stigmatizing of DSM diagnoses, and their behavior is more likely to be interpreted "willfully," as manifestations of bad behavior or fakery, than it is as a disability issue. In what ways, for example, is your institution willing to work with — and accommodate — graduate students who cannot afford testing for, say, ADHD? In what ways is your institution willing to consider neurodivergent modes of bodying — such as tics, stims, stutters, or meltdowns — as languages and expressions that enrich our classrooms rather than merely disrupting them?

Importantly, disabled graduate students *are* leaders, many of whom have routinely been forced to take on additional labor in relation to disability climate and broader accessibility. A number of disability hashtags on Twitter demarcate the efforts graduate students routinely commit to campus disability issues. (Some examples include #AcademicAbleism, #ADHDPhD, #AutisticsinAcademia, and #PhDchat, as affiliated/combined with relevant disability hashtags.) Were we to actively spend

time on the #academicableism hashtag, for example, we would learn more about disabled students' (and marginalized students' more broadly) experiences with the GRE, which are overwhelmingly negative. One Twitter user, for example, remarks that being disabled requires an extra 20 page form plus an additional 4 to 6 weeks in order to even *take* the test. The *GRE Bulletin Supplement for Test Takers with Disabilities or Health-related Needs*, which contains lengthy instructions for the accommodation process and timeline, is a microcosm of bureaucracy in action, laying out the extra time, steps, and labor that disabled students must expend simply to secure so-called "equal access" to take the exam. (Recall that these efforts do not assist students in performing well on or finishing the exam.) At one point, the *Bulletin* notes, "While many test takers with disabilities successfully take a GRE test with appropriate accommodations, some test takers with disabilities may want to ask their prospective institution or fellowship sponsor whether it is willing to waive the test requirement and consider their application based on other information" (p. 4). ETS's appeals to appropriateness here is a none-too-subtle suggestion that if one cannot take the test with the accommodations they offer, then one is making unreasonable demands. The continued appeal to "appropriateness," in combination with the outsourcing of all culpability on the part of ETS (instructing prospective students to seek waivers from programs that are about to evaluate them) reinforces the notion that disability is an individual issue that can be incompatible with the mores of academic life and procedure. In response to these issues, and more, the hashtag #GRExit elaborates the myriad ways in which the GRE actively instills hurdles and creates the inequitable conditions it is claiming to combat.

3. Advocate for accommodations while also working to move beyond them

This is the point on which I will end. Even though much of my talk today has provided stringent critique of accommodationist systems, these accommodations are often the only avenue in place for disabled students to gain access to the university. Even though accommodations individualize disability and reinforce notions of reasonableness over true access, we need to advocate for our graduate students. One starting point here is for graduate programs to learn the fine-grained

details about how the accommodation process at our institutions work — most especially for program milestones beyond coursework (capstones, exams, theses) and in graduate assistantships. How and where does your institution's disability services office actively serve and center graduate students, and in ways that depart from an undergraduate-centric checklist of standard accommodations?

Consider, too, how graduate faculty represent and understand accommodations in their graduate-level courses. If you were to audit graduate-level syllabi, what disability boilerplate will you (or won't you) find? If your institution requires boilerplate, where does such boilerplate recognize disabled students as valuable contributors whose embodiment enriches the classroom, and where does such boilerplate represent disability as a condition of bureaucracy, disruption, procedure, or hassle? In "[Suggested Practices for Syllabus Accessibility Statements](#)," Tara Wood and Shannon Madden provide a number of examples for designing disability-positive syllabus statements, exhorting us that "Now is the time to move beyond meeting legal obligations, obligations that resulted from years of hard-fought battles for civil rights for individuals with disabilities, and into thoughtful construction of accessibility statements that allow for adaptable, universal access to our pedagogies and classroom spaces" (n.p.). Wood and Madden suggest that such statements incorporate flexibility and different modes of learning, represent disability access as a collaboration rather than a piece of paper descended from On High, and welcome opportunities for alternative modes and delivery in the work of the class.

If your institution's accommodation system is adversarial, requiring approval from students' graduate studies directors or other administrators, then this is an opportunity for your graduate school to intervene and potentially serve a more direct advocacy role on behalf of its students. (To leave milestones accommodations solely up to the discretion of individual DGSs, I'd argue, can result in inconsistency, unfairness, and inequity.) More than, this, however, consider what it might mean to enable access without requiring a lengthy accommodation and documentation process. What would it mean to grant extra time requests for preliminary exams without requiring registration and

documentation? What might it mean to believe students, to valorize flexibility and collaborative access over rigor and reasonability?

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