The Struggle You Can't See

Experiences of Neurodivergent and Invisibly Disabled Students in Higher Education

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Conclusions

Sometimes one experience changes a person in such a way that it opens the door to more. This can occur in a negative direction, such as when a staff member's negative reaction to a disability disclosure leads a student not to seek help again in the future, or in a positive direction, as when watching a parent fight for their rights bolsters a student's understanding of their own worth and power. Sometimes the direction is neither uncomplicatedly positive nor negative. Since sitting on the couch beside my friend and understanding that she really could not do what was asked of her, since sitting with myself and realizing that my neurochemistry had failed me and not my strength of character, I have been humbled to find more and more other students willing to make me privy to their struggles. Somewhat ironically, given the topic of this book, this has become more common still since my chronic illness progressed to the point that I began to use a wheelchair when navigating campus. Even we, the invisible, are conditioned to look for the same visible markers of authenticity that others do.

The voices in the studies included in this book echo the voices I have heard personally. Students vent feelings to me that have clearly been pent up for years, if not decades. They complain of inaccessible library resources, which I gratefully take back to see what can be better, in spite of the complications and challenges that are always involved at levels beyond our control. They tell horror stories of casual cruelty and fundamental exclusion, with resigned familiarity. They cry in my office as they try to understand why an instructor seems to consider them unworthy of even simple adjustments to make it possible for them to fully participate in the vital human work of learning, why they feel seen only as demanding wastes of time and effort. Aloud or unspokenly, as others have to their faces, they wonder if they should even be here at all.

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Worth the Struggle (But Better Without It)

It can be hard not to wonder the same thing, though from the student's perspective rather than an exclusionary one. After all of the many difficulties, problems, and concerns that this book admittedly describes, one might well begin to wonder: is higher education even worth the burdens it entails for neurodivergent and invisibly disabled students? I would argue strongly that the answer is yes, however, and with students' own voices as my greatest source of evidence. As mentioned in the section on motivation in Chapter 4, students across studies speak of the pleasure, pride, and value they find in multiple aspects of higher education.[1] Even as it may reflect internalized ableism for students to reject supports because they want to succeed 'on their own,' at the same time, it conveys a more affecting message: these students do want to succeed academically, and to be able to take pride in that accomplishment by their own standards. Their narratives recount numerous examples of what has been good about higher education for them, as well as bad: transformative, positive experiences with disability services staff (Lightfoot et al., 2018; Zeedyk et al., 2019), faculty (Ward & Webster, 2018; Kutscher & Tuckwiller, 2019), peers (Ness et al., 2014; Turosak & Siwierka, 2021), and their own increased self-knowledge and self-acceptance (Brandt & McIntyre, 2016). There has also been empirical evidence gathered to suggest that, although being disabled does correlate to lower work quality and earnings in employment even for college graduates compared to the nondisabled (Phillips et al., 2022), employment earnings and quality are significantly improved for people with disabilities if they hold a college degree (O'Neill et al., 2015; Phillips et al., 2022).

There is ample evidence that, in spite of all the challenges of higher education, its benefits for neurodivergent and invisibly disabled students are just as great as for their neurotypical and nondisabled counterparts. The primary difference is in the costs: for the students whose narratives are described here, far more effort, trauma, and material resources are the price of the same benefits. All of this only underscores the urgency

1 Ashby & Causton-Theoharis, 2012, Cullen, 2013; Drake, 2014; Ness et al., 2014; Ennals et al., 2015; Anderson et al., 2017; Vincent et al., 2017; Lambert & Dryer, 2018; Lightfoot et al., 2018; Ward & Webster, 2018.

of decreasing those costs and barriers for invisibly disabled and neurodivergent students, and increasing the equity of their experiences with those of other students. There is clear value for them in what higher education has to offer, and it is vital for that value to be made more accessible.

Students as Partners in Justice

Perhaps the most critical factor in making this possible, at the same time, will be listening to these students' voices, trusting their experiences and their desire to learn, and respecting their expertise as partners in making positive change. This begins with resistance to the neoliberal and carceral attitudes that position students, particularly those who do not conform to an imagined ideal in their characteristics and needs, as dishonest manipulators and costly liabilities. In Chapter 3 of *Academic Ableism*, 'Imaginary College Students,' Dolmage approaches this problem by dissecting the opposed ideal and anti-ideal characters that educational decision-makers seem so often to imagine as their students: newly multi-literate and transformative digital natives versus resource-draining and possibly malingering laggards with 'new' disability diagnoses, the latter of whom are full of demands that will only hold back the capitalist potential of the former. The authors who argue against removing documentation barriers to students' accommodations certainly seem uncritical of this construction. The problem, however, is that neither the ideal nor the anti-ideal student is real. They are simply one positive and one negative way of framing essentially the same challenge to educators: to develop more sophisticated, innovative, and effective systems and strategies that facilitate the greatest possible success for all students in higher education. In considering the changing characteristics of their students, Dolmage suggests that educators 'might move forward by recognizing that an expanded range of expressive possibilities, instead of creating new ways to be inferior, and instead of hiding inequities under the costume of progress, offer new contact points for engaging with the difficult work of teaching and learning' (p. 114). Why, then, should this challenge only be a negative one when it comes from disabled students? To take this a step further still, given the broad and multifaceted range of human difference, might there not be

more gain than loss from drastically loosening higher education's rigid criteria for what constitutes 'deserving' support and flexibility?

If we divest from the 'politics of disposability' as named by Giroux (2014), and truly view our mission as one of meeting the educational needs of *all* students, not only those who offer the greatest profit margin, or need the least and in the most convenient ways, then we will find ourselves required to engage in the tremendous work of changing higher education fundamentally for the better. This cannot be meaningfully achieved, however, without giving priority to the agency and lived experience of disabled and neurodivergent students, and especially those with other intersecting marginalized identities. This is fundamentally Berne's (2015) 'leadership by those most impacted,' as well as the core tenet of DSE to 'privilege the interest, agendas, and voices of people labeled with disability/disabled people' (AERA, 2024). This also, in turn, cannot be achieved by perceiving students as defined by deficits, as lazy and passive, as problems to be solved—or worse yet, as schemers constantly looking to put one over on us for their own benefit. Sometimes students are disengaged, and sometimes they engage in academic dishonesty; there may often be more complex reasons, challenges and inequities behind these actions than we imagine, but they are real occurrences, certainly. There are strategies and processes that can manage these occurrences when they happen, as problematic as many of these may also be in application. If we treat every student by default as a resistor or a suspect, however, we do not only lose the opportunity to know and collaborate with whole people, who can offer powerful insight and partnership in how the work of education could be better. We also create the conditions for that presumption of misbehavior to land doubly on those most vulnerable, students who are most likely to be perceived as threats and even potential criminals because of marginalized identities: Black students, psychiatrically disabled students, LGBTQ+ students, and more. Trusting our students can be vulnerable and a risk, but it is also a moral and a professional imperative. In line with the Freirean principle of dialogue, for those with more power to embrace humility, lay our power down, and see our students as equal partners is crucial to the work not only of education, but of becoming more fully human:

> Dialogue, as the encounter of those addressed to the common task of learning and acting, is broken if the parties (or one of them) lack humility. How can I dialogue if I always project ignorance onto others and never perceive my own? . . . At the point of encounter there are neither utter ignoramuses nor perfect sages; there are only people who are attempting, together, to learn more than they now know. (Freire, 1970/2014, p. 90)

Putting in the work to release our assumptions and suspicions, and from there being able to enter into genuine dialogue with our students, is the first and most monumental step. All the other directions for change that have been suggested by these narratives come afterward.

Key Themes for Systemic Change

Inequitable Time and Energy Demands

Unquestionably, this is one of the most recurring themes throughout the narratives of students in every category, and one of the core barriers to academic success and positive experiences. University is substantially harder and more time-consuming for these students than it is for comparable nondisabled and neurotypical peers. Every more minor barrier described feeds into this one, and this disadvantage of time and effort not only makes students unhappier and less likely to make good grades and graduate on time, it puts their mental and physical health at risk. Furthermore, while help may be available to try to lessen this burden, having to seek out that help often actually increases it. Many students also either have reasons not to seek help, do not know help is available, or do not even realize that their experiences are so much more difficult that they might need it. 'Accommodations and supports by request, with proof of need' is simply not a model sufficient to meet these students' challenges. Despite the dedication, hard work, and compassion of disability services staff, every piece of evidence suggests that the overall structure itself works for vanishingly few of those who are most in need of it.

What, then, is the alternative? This is where new possibilities have yet to be imagined, and it will be no simple task. How could higher education institutions, as a complete system, internalize the idea that every student needs and deserves support, services, flexibility, and

individuation? Perhaps more importantly, even if they did, would they have the appropriate resources to act accordingly? It is difficult to imagine the answer is yes, no matter how creative and restructured an implemented approach might be. To be sufficiently resourced to truly make higher education accessible, institutions would need substantially more material support from without as well as within, at the level of the state. This would also ease the burden on students to be the institution's primary income stream, which as demonstrated creates inequities for the 'less profitable' students who require more resources to succeed, and adds to their already disproportionate financial burdens. It is not only higher education that must expand its imagination, but broader culture too. If higher education is to serve young adults not only as a checked box for better employment, but as the training in critical independent thought needed to navigate an increasingly morally complex and fraught world, it cannot continue to be treated like an expensive, selective luxury by institutions and legislators. The dissonance in our collective vision in the United States of what higher education is and is for will only continue to widen existing gulfs of income inequality, if it is allowed to persist indefinitely. As Giroux (2014) summarizes,

> The public has apparently given up on the idea of either funding higher education or valuing it as a public good indispensable to the life of any viable democracy. This is all the more reason for academics to be at the forefront of a coalition of activists, public servants, and others in both rejecting the growing corporate management of higher education and developing a new discourse in which the university, and particularly the humanities, can be defended as a vital social and public institution in a democratic society. (p. 20).

This is not, however, to say that all of the problems lie outside the doors of higher education.

The Need for Accountability and Support at All Levels

Why do staff, and especially faculty, emerge so universally as one of students' greatest supports when they are compassionate and accommodating, and one of students' greatest barriers when they are not? More than anything else, this pattern indicates the amount of power that people in these roles hold over students, for good or ill, at least in the

context of their education. Because of this power imbalance, seemingly small decisions that faculty and staff make in dealing with students can have a disproportionately large impact on students' experiences, positive or negative. This invests faculty with the responsibility to take particular care with their personal biases and behavior, but this is not a responsibility that all faculty equally recognize. The good news about this, however, is that a few tangible and significant things educators can do to improve students' experiences lie in our hands: simply offering compassion, flexibility, and cooperation.

The bad news is that the vast majority of staff and faculty who are not predisposed to do these things are also undoubtedly not reading this book. We see this play out time and again in professional development programming on accessibility and other issues of diversity, equity, and inclusion: those who least need education on these matters show up, because they are already invested, and those most in need do not, because they are not. Furthermore, and more importantly, few if any accountability structures exist in most institutions to ensure that faculty and staff must consider it a priority regardless. As with the inequities imposed on students by the systems of higher education, this is not a problem that individual choices can entirely address. Neither, for that matter, is it a problem that individual choices entirely caused. I would imagine that most faculty who balk at accommodations, insist on pedagogically unnecessary and inaccessible format elements, and even make callous remarks to students do so not out of malice or even necessarily out of apathy. In the majority of cases, I believe the more likely culprits are lack of knowledge, lack of awareness, and the impact of stress from being severely overworked and under-resourced themselves. As I mentioned in the introduction, most faculty are not in the position to witness the real emotional, psychological, and physical distress that their behavior worsens; most students try strenuously to avoid being emotionally vulnerable enough with faculty to display that distress, and with good reason. Lacking this insight as well as adequate preparation and resources for inclusive instruction, it could be easy for a harried, overburdened instructor in an understaffed department to miss the great personal cost of a student's asking for help at all, and dismiss it as the product of laziness or lack of commitment rather than the real need it represents. Such an instructor is even less likely to spontaneously

put in work to improve the accessibility of their courses, for the sake of students who choose not to ask for help at all.

The more significant and systemic problem is that faculty, even more than staff, are not consistently trained, supported, and incentivized to facilitate the success of marginalized students, including that of disabled and neurodivergent students. As I have mentioned, even basic pedagogical skills are not reliably components of the degree programs that credential college and university faculty, let alone inclusive and culturally relevant pedagogies. Erosion of full-time employment and tenure continue to increase the time and effort burdens on faculty of all types, and under these conditions, only the most passionate about working to improve instruction for marginalized students will do so. This is especially true when faculty are also not evaluated on this work consistently or, in many cases, at all. Furthermore, the faculty invested enough to devote extra, unrecognized work to teaching inclusively are most commonly those who are marginalized themselves, increasing time and effort inequalities at their level as well. For these problems to begin to be rectified, it will be necessary for institutions to commit to ensuring that faculty are fully prepared to teach all types of students, to investing the resources to ensure that they have time, funding, and support to do so, and to consistently hold them accountable for this work in tangible ways. Neither should tenure, I will argue, enable a faculty member to refuse to support equity for marginalized students, if instruction is to be truly equitable for all. Tenure is vital to protect academic freedom, but should not grant a freedom to succumb to biases and exacerbate inequities. Faculty and staff deserve access to support, resources, and preparation, but students also deserve ready access to channels of restorative justice should they experience harm. Employees' rights should be respected, and so should students', and balanced with great care where they conflict.

Before all of this will be possible, however, institutions themselves will also need to be held accountable for implementing it, as well as adequately resourced to do so. Even as the issues are not fully resolvable by an individual staff or faculty member, they are also not fully resolvable by an individual institution. Lack of standardization and accountability in how disabled and neurodivergent students are supported has led to broad inconsistency in the implementation of legislative requirements

from one institution to the next, which in turn creates inequity from the very moment that students select colleges and universities to which to apply. For the most part, furthermore, those institutions with poorer support systems have them not deliberately, but because—just as with faculty—they lack access to sufficient resources to provide better, and simultaneously are not held sufficiently accountable for doing so. Failure to follow through on the promise of education for all disabled people, and all that it entails, is a problem with roots at the national level, not just the local one. It will take change at the national level to rectify it in any systematic and comprehensive way.

The Need to Create Human Connections

Although power imbalances make the issue starkest with faculty and staff, the critical importance of other people as supports (and barriers) goes far beyond them. The support of family members is a powerful asset to students, from academic work to daily living activities to housing conditions—and it is only available to those whose family are available, supportive, and able to devote sufficient time and resources to it. The support of peers and friends is cited time and again as one of the factors most beneficial to students—and it is only available to those who successfully develop strong friendships and support networks for themselves. The large influence of these connections is cause for concern, considering that some students in these categories are so likely to have significant social challenges and family tensions. The presence of this type of support is much appreciated, but this also means that its absence is keenly felt, and may widen existing gulfs of inequity.

It is important for faculty and staff to recognize the tremendous influence that other people in students' lives have on their success, and not take for granted that students already have access to those connections. While in most cases these may be personal and non-academic supports for students, it would nonetheless be greatly beneficial for the academic institution to take a more active role in facilitating connections for students, to assist those who most need it in finding informal as well as formal support. There is a place for work to be done that connects disabled and neurodivergent students to other disabled and neurodivergent students, as well as connecting them to

nondisabled and neurotypical student peers, to staff, to faculty, to counselors, to medical professionals, and more. Even at the formal level, another of the supports for which students most clearly express need is lasting, individual connections to people. They need staff members who get to know them, learn and work with their individual characteristics, and connect and coordinate with others to communicate about them in a holistic way. This is something from which invisibly disabled and neurodivergent students would certainly benefit, but it seems equally certain that a majority of other students would, as well, whether they have a known learning difference or not. At the same time, however, advising and counseling services at many institutions seem to become less comprehensive and personalized as time goes by, not more. What is preventing this type of individual case management for students is not a lack of need, but a lack of resources, mainly human but also well beyond that. A major reimagination of the functioning of higher education would be necessary to be able to consider meeting this need, but it would be extremely worthy of consideration.

Next Steps

In each of these cases, as I have repeated, the work is larger than any one individual person, or any one individual institution. This does not mean, however, that individuals can do nothing to improve matters, particularly in the shorter term. High-level, systemic change may be needed, but systemic change occurs through the collective action of individuals. Furthermore, there are individual actions—such as improving course structure and offering compassion as a faculty member—that do make a difference for individual students, even if they may not substantively address the underlying problems. Even the smallest things are worth doing, if they improve students' lives in some way. The smaller actions we are able to take in the short term also have the potential to lay groundwork for broader future changes, as they are possible to implement. Chapters 7 and 8 point to many of these more modest places to begin, with the caution that they should not be implemented in ways that reinforce existing ableist attitudes, nor confused with the most critical work that is needed.

That most critical work, instead, begins with coalition-building and advocacy. Those who are supportive of neurodivergent and disabled students are too often not explicitly identified on campus, but we do exist, and many of us would like to see conditions improved for our students. Armed with increasing knowledge of what most often helps and hinders students, we can turn our attention to joining forces with students and with one another, and using our voices to support change at multiple levels: within our departments and offices, within the institution, in the state, and nationally. If greater funding, resources, and state support are needed to improve conditions substantively for students, then that argument needs to be made to those who are able to grant those things, as well as demonstration of the current inequities at work. The evidence exists, ready to be used; I hope that if this book serves no other purpose, it serves to present and organize that evidence. I hope it can be put to good use in persuading others of the urgency of this matter.

On that subject, although clearly a great deal of research already exists on these students' experiences, gaps and potential directions for future research have also been revealed by this work. Given the patterns I have noted on the overwhelming whiteness of participants in studies of neurodivergent students, there is a clear need for more research specifically on the experiences and needs of neurodivergent students of color. In particular, Black and Latino/a/e voices have been significantly underrepresented in the research to date on neurodivergent students and other young adults, and it will be critical to expand the literature in this direction in the future. As I also noted, there were also several types of conditions that would have been helpful to add to my list of categories in this study, but I was unable to do so simply because of the lack of existing research available. In particular, the relative absence of specific information on students with dyscalculia, dysgraphia, dyspraxia, and Tourette Syndrome is a significant limitation of the present study, and the body of research on neurodivergent and invisibly disabled students would benefit from specific studies focused on these conditions in the future. Although there was sufficient literature to include traumatic brain injuries as a category, literature in this area is also substantially sparser than for the other categories examined, and therefore the conclusions

regarding these students may not be as robust or reliable. Additional research on the experiences of students with TBI is also needed.

More broadly, while it is heartening that discussions of ableism in higher education and academia are gaining traction in recent years (see for example the works of Dolmage, Price, and Brown and Leigh, among others), there is still more work to do in expanding on this topic and foregrounding it in more mainstream scholarship. Topics of disability and ableism, while increasingly prominent, remain relatively niche outside of disability studies in much of the academy. As mentioned, another topic only beginning to gain traction as a subject of serious study, and highly relevant to the discussion here, is that of time poverty, especially as it relates to higher education. Further study of the role of time poverty in the lives of college students and disabled people in particular, as well as those who are both, would likely offer a great deal of additional insight, and produce additional evidence about how deeply change is needed.