The Struggle You Can't See

Experiences of Neurodivergent and Invisibly Disabled Students in Higher Education

Ash Lierman

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Introduction

Purpose, Approach, and Guiding Principles

At this point in my early forties, I have quite literally lost count of the number of my friends and colleagues who have been diagnosed with life-altering abbreviations: ADHD, BPD, ME, GAD, and more. Almost universally, at least in my personal sphere of experience, these diagnoses were also made not in their childhood, but far later. The string of letters that changed everything only appeared in their lives at thirty, at thirty-five, at forty—but in retrospect, it became an explanation that brought on a torrent of emotional relief, regret, and belated understanding. Some of these people I had known for long enough to share that torrent. I was able to recall vivid memories of a younger friend breaking down in tears on the sofa in my apartment, for example, as she tried to force herself to complete an assignment for a college class with my wife and me present for accountability, but still failed to even begin. I remember being bewildered, at the time, as to what the problem could be, and why what seemed to me like a relatively simple task could be so impossible for her. Even so, though, in the face of her tears of frustration, I could not doubt that it was.

Even as hearing her diagnosis finally made sense of that memory, though, it also connected other uncomfortable dots in my mind. After all, I had received my own string of letters some time earlier, although still only when I was nearly thirty years old. Mine was OCD: which does not stand for someone's thoughtless joke about preferring order and cleanliness, but for diagnosed obsessive-compulsive disorder, and chronic depression along with it. As I reviewed my own experiences as a college student, I realized that although starting a paper had never been an insurmountable task for me personally, at times other things had

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been that would have seemed equally simple to anyone else: sleeping through the night, getting out of bed in the morning to attend classes and examinations, joining conversations in class, and sharing a room with another person, to name a few. I had just assumed that, although these felt like impossibilities for no reason I could understand, it must actually only be laziness and weakness of moral character that made them feel that way, since so many adults in my life so far had already been at pains to tell me so. I have no doubt that my friend assumed the same in her case.

All the same, I genuinely believe that most of the educators who became frustrated with me as a child, adolescent, and young adult had my best interests at heart, and would have helped me if they had been able. Not every educator has personally experienced being a student trying to cope with seemingly impossible tasks, or has completely unpacked that experience even if they have. Even faculty and staff who work directly with students, for that matter, are not always in the position of being present at the moment when an aspect of a student's body or mind proves to be completely incompatible with rigid academic demands. My young friend's professors were not able to sit on the sofa beside her, witnessing with their own eyes that her failure was not for any lack of trying. When a student has unique needs that are not outwardly visible, there are few opportunities to see personally the evidence of just how real and severe their struggle is. The students themselves may not even realize that what they are experiencing is far more difficult than it should be.

If students are to succeed in higher education, in a way that is equally accessible and fair to all, it is imperative to reduce the number of experiences like those my friend and I had. Invisibly disabled and neurodivergent students should not have to go through higher education under disproportionate, isolating burdens, facing seemingly impossible demands that are treated like simple tasks, and not even understanding why. To accomplish this, however, the educators, families, and peers of those students will have to learn more about what we can't always see: which is what those students actually experience in college. In many cases, the students themselves need to be helped to see it better, too.

The Purpose of This Book

To this end, this book aims to compile existing research on neurodivergent and invisibly disabled students' experiences in higher education, mostly in English-speaking countries around the world, in a comprehensive and organized way. By this time, there is an extensive body of scholarly and professional literature available on this topic. Hundreds of studies have been published based on interviews with students individually or in groups, all sharing a single diagnosis or all facing different types of challenges, in which the students recount to an interviewer their experiences, barriers, supports, and suggestions for improvement in the college environment. What does not seem to have been attempted to date, however, is a truly broad analysis of the themes and patterns in this literature, which brings together multiple threads of similar types of experience and examines where they overlap, where they agree, and what they suggest. This book attempts to fill that gap, by identifying the things that invisibly disabled and neurodivergent students have already told us, in study after study, hurt and help them most in higher education.

This information will be of value, of course, to staff and faculty in higher education who work with students of all kinds, and want to know what they and their institutions can do to better serve this specific population. It will also, however, be of value for anyone who is interested in learning what these students experience in college, and, as mentioned above, that includes invisibly disabled and neurodivergent students themselves. 'Invisibly disabled and neurodivergent' (an admittedly unwieldy category that will be unpacked more fully in Chapter 2) encompasses a very broad variety of differences, many of them extremely similar to one another in some ways and extremely different from one another in others. Even two students who share the same diagnosis will not always share the same traits, needs, preferences, and experiences. The stigma and anxiety that students may experience around disclosing and discussing their disabilities, furthermore, means that disabled and neurodivergent students are often disconnected from their peers with similar conditions, with no ready means of communicating and comparing experiences. Most invisibly disabled and neurodivergent students know only what it is like to go through college as themselves, and may have little sense of just how common their challenges and observations really are. As a result, they may assume that a particular problem is their own personal failing, rather than a systemic injustice being inflicted upon them by a higher education institution insufficiently equipped to provide them with what they need.

This book, therefore, may also be eye-opening for the same students whose narratives fill it. It is my hope, in fact, that they will learn that others are going through and wishing for the same things that they are, and that they feel increasingly empowered to speak up, join together, and demand change. At the same time, I also hope that this book will serve as a basis of evidence from which higher education faculty, staff, and administrators can not only make adjustments to their own individual practice, but also advocate for more sweeping changes in institution-level committees, task forces, and governance. As the issues and needs identified by the students in these pages are bigger than any one student's story, so they are also larger than any one educator's scope of influence can resolve. Knowing what they are, however, can be our starting point for coalition-building and working together for a better and more equitable environment for all students in the future.

Guiding Principles and Positionality

As an academic librarian educator specializing in instructional technologies and instructional design, my core philosophy in my work sits at the nexus of human-centered design and learner-centered teaching. The two approaches have an interesting set of overlaps and divergences, not always evident to those inexperienced in the ways instructional design brings them into conversation. As described by Norman (2013), among its other proponents, human-centered design emphasizes starting from thorough examination of real people's real needs and habits in order to create objects, spaces, and technologies that will be intuitive for them to use successfully (pp. 8–10). Learner-centered teaching, meanwhile, focuses on changing the instructor's traditional role as leader and authority of the classroom to a supportive role, so that students take primary responsibility for directing and controlling their learning, and their experience and mastery are central (Weimer, 2013). While the contexts, particulars, and goals vary between these two philosophies, a core element is shared between them: both concede most of the power and authority traditionally afforded to the expert (the designer, the educator), and offer renewed recognition and respect for the perspectives of the supposed non-expert (the user, the student), whose success has ostensibly been the point of the exercise all along. To put it bluntly, both are conscious, collaborative exercises in humility, and this fact sometimes causes experts in both fields to balk at their implementation.

To my mind, however, both are imperative if we are actually to develop experiences—learning and otherwise—that meet the needs of those we entered our professions to serve. Toward this end, I chose to begin from the spirit of inquiry that is fundamental to both approaches. Rather than limit my creativity and effectiveness by simply collecting and replicating existing services for invisibly disabled and neurodivergent students, which might or might not actually be best serving the needs of students in practice, I instead sought out available records of students' self-described experiences of higher education, positive and negative. Even as a disabled educator myself, I have only one perspective on what is helpful and harmful in higher education, and I felt that it would be necessary to investigate students' perspectives as thoroughly as possible before I could have any confidence in correctly identifying the problems most in need of solutions.

On a similar note, I have chosen to ground this work in a disability studies in education (DSE) theoretical framework, informed by elements of Disability Critical Race Theory (DisCrit). DSE embraces the social model of disability, and seeks to challenge the prevalent educational understanding of disability as a medicalized deficit to be overcome by the individual. Instead, this understanding positions disability as one of many identities an individual may hold that are systematically marginalized, in intersecting ways, by educational systems and the broader society. Transforming access, equity, and inclusion for disabled people in education is thereby a matter of social justice and liberation, and the disabling impacts that they experience for not conforming to prescriptive expectations of physical and mental functioning are not individual burdens disabled people must bear, but social and systemic failures to meet their needs that must be addressed. DisCrit, meanwhile, marries disability studies and critical race theory perspectives in education research to create a fundamentally intersectional lens, which critically investigates the interactions of race-based and ability-based oppressions in education, particularly with regard to economic and carceral injustice (Connor et al., 2016). These approaches have guided my investigation of students' stories throughout this work, as has my personal commitment to activist principles of disability justice: that the societal structures that oppress disabled people need to be challenged as an inextricable component of challenging all interconnected forms of marginalization, by resisting capitalist commodification and carceral policing of bodies and minds, by rejecting the idea of a 'normal' body and mind and embracing the equal value of all, and by embracing solidarity and collective liberation across identities and communities (Berne, 2015). This radical position shares roots in common with the neurodiversity paradigm, which will be discussed in more detail in the early chapters of this book, and I believe strongly that the level of reform and revolution it advocates will be necessary if we are to pursue true justice and equity for all members of our society.

This book proceeds from the same assumptions, and among them is the principle Berne (2015) outlines of 'Leadership by Those Most Impacted,' a related concept to the one that disability activists have often stated as 'nothing about us without us.' I see myself as undertaking this work in order to lead a conversation as one of those who have been most impacted, but in so doing, I have also let the voices of students lead me. Foregrounding the voices of disabled students, staff, and faculty is a priority that has been identified for the continued course of educational research (Seale, 2017), both in the interest of completeness of information and from a social justice standpoint. It has been one of my primary goals throughout this project, and has greatly informed the research and construction of this book.

Methodological Approach

As alluded to above, the method I selected for the present study was effectively a massive narrative literature review. Given my professional expertise as an academic librarian, which centers on information organization and literature searching and synthesis, combined with the wealth of largely uncompiled qualitative data available, this seemed to be the most suitable way to begin. Rather than conducting my own qualitative research with what would surely be a relatively limited sample size, I could use the existing literature to create a foundation for my and others' future research, by collecting and analyzing the broadest possible variety of rich descriptions of student experiences. With my primary focus on simply capturing student voices where they appeared in the literature, I was less concerned with the quality of research in individual studies than I might otherwise have been, and ultimately chose to broaden my scope to include theses and dissertations, as well as published peer-reviewed books and articles. I also found that the comprehensiveness and specificity of the dissertation format seemed often to lend itself to the types of analysis I was seeking, and this was particularly true of dissertations studying only students with a certain identity or diagnosis.

Because I had a set of specific named conditions or types of conditions in mind for consideration (I discuss the reasoning behind this selection in more detail in Chapter 2), I let those names lead me in the construction of my search terms. My overall search strategy was to conduct seven distinct, overlapping searches, focused on:

1. Generalized terminology such as 'neurodivergent,' 'invisibly disabled,' and similar terms;
2. Dyslexia and variations, including loosely related conditions such as dyscalculia and dyspraxia;
3. Autism and variations, including now-outdated terminology such as 'Asperger's syndrome';
4. Attention deficit hyperactivity disorder or ADHD;
5. A number of variations on the concept of mental illness and mental health disorders, of which I found 'psychiatric disabilities' emerged as the most commonplace;
6. Traumatic brain injuries and variations; and
7. Chronic illness and variations, including names of specific commonly invisible conditions, e.g. Ehlers-Danlos syndrome, inflammatory bowel disease, etc.

In each case, these terms were paired with terms identifying the possible types of study of interest to me, such as interviews, focus groups, qualitative surveys, and similar. I repeated this search across multiple education subject databases, as well as in thesis and dissertation databases, and hand-selected possible candidates from the results. In some cases, I was also able to uncover additional sources from thorough examination of the literature reviews and citations of the studies I included.

Given the sheer amount of literature that could potentially have been encompassed by this approach, I also keenly felt the importance of limiting the scope of my review only to what was of primary interest. For the process of selecting studies from my initial results sets, I developed a set of stringent criteria for inclusion, as follows:

- Only studies that presented student voices directly were added. These could take the form of summaries of and quotations from interviews, survey responses, or similar, but quantitative survey responses were not included.
- Studies were excluded if their findings related only to coursework, teaching faculty, university-level accommodations, or combinations of these. While these studies would be useful for teaching faculty or for disability services staff, they would have little relevance for others in academic support roles with minimal influence over these factors, including myself. Many findings of this study do relate to coursework and accommodations, but these are generally recorded in the context of more broadly applicable findings and conclusions.
- Studies were also excluded if their primary focus was the transition from high school to college, mainly because this is a broad enough topic in itself to warrant a separate investigation. As with coursework and accommodations, some information is included here on challenges for new college students, but the primary focus is on students who are established at the postsecondary level.
- Studies were also excluded if their primary focus was on evaluating the success of a particular program or intervention, since my goal was to focus on broader experiences rather than students' reactions to specific attempts at solutions.
- Studies were considered from all types of postsecondary institution and from any geographic location. As I was only

able to consider English-language studies, the majority of included studies were conducted with students from the United States, Canada, the United Kingdom, and Australia, although some studies from mainland European nations, African nations, and a few others were also included.

- In general, only studies published in 2011 or later were considered, as inclusive practices change and develop rapidly and therefore it was preferable to only examine contributions from the preceding decade. This cutoff date was flexible, however, with some slightly earlier studies included if they were found to be sufficiently cited by and significant to subsequent research.

These guidelines served to define the main body of literature used in this study, for a total of approximately 180 articles, book chapters, and dissertations. I worked systematically through the results of each individual search, examining findings and identifying recurring themes, both for students in each grouping and held in common across multiple groupings. My findings have been organized by theme into the chapters that make up Part II of this book.

It should be noted explicitly, however, that as much of a wealth of information as I was able to synthesize using this approach, it is severely limited in at least one respect: the predominance of white study participants. A substantive critique of the existing literature on disability in higher education is its centering the experiences of white students while failing to meaningfully engage with the impacts of race on disabled students (Stapleton & James, 2020), and I have found this to affect the vast majority of studies I examined, with many describing overwhelmingly or entirely white participant pools, if the race of participants is identified at all. I eagerly anticipate future growth in the body of literature on the experiences of disabled students of color, as this is a significant gap in dire need of being addressed. Working with the available literature in the meantime, however, while I doubt I could fully compensate for this concern, I have made a deliberate effort to address it. A full chapter has been devoted to literature that would otherwise have been out of scope for this review, but that reveals intersectional considerations that may impact disabled and neurodivergent students with other marginalized identities. I have also taken care to note ways in which minoritized racial identities may specifically impact student experiences reported in the literature, wherever they arise. Even so, the whiteness of the participants in the core literature under discussion here should remain front of mind when considering its conclusions, and the relative absence of the voices of students of color necessarily limits any claims I can make as to their generalizability.

Structure

Part I, Foundations, begins by establishing the context into which this work enters, as well as its terms and parameters. Chapter 1 discusses the landscape of higher education as it pertains to disabled students in general, and invisibly disabled and neurodivergent students in particular. It provides a brief overview of the history of disabled students' inclusion in higher education, including relevant movements and legislation, and then addresses the major thematic barriers that disabled students still encounter to this day: the power structures inherent in higher education in its present form, the restraints on the capacity of institutions and their staff, neoliberal attitudes and academic capitalism in colleges and universities, and specific stigmas around learning and psychiatric disabilities in college students. With these factors in mind, Chapter 2 outlines the terminology and categories in use to name and organize neurodivergent and invisibly disabled students in this work, and the reasoning behind their selection. It also addresses the limitations of these rhetorical constructions, and the nuances that make them less simple in practical fact than they may appear on the page.

In Part II, Challenges, the main body of research is laid out in a series of themed chapters. Chapter 3 discusses students' experiences of institutional systems and disability services offices and personnel, including the overall challenges presented by institutions and their accommodations processes, and issues around choices of learning modality, as well as the tensions of self-advocacy, disclosure, and help-seeking that students experience, such as the barriers and benefits around acknowledging their conditions and seeking support, issues around diagnosis, and the role of disability identity. Chapter 4 describes students' experiences in the curriculum and classroom, and what serves them most and least in terms of faculty attitudes, the intrinsic academic strengths and weaknesses associated with the categories discussed here, and different elements of course structure and instructional delivery. Chapter 5 discusses student life experiences outside of the curriculum, meanwhile, including social issues and relationships with peers, mental health challenges, and the physical environment on campus. Chapter 6 then turns particular attention to intersectional considerations, including how disabled and neurodivergent students' experiences are impacted by additionally minoritized racial and ethnic, gender, and LGBTQ+ identities, as well as by trauma experiences, which are relatively common for disabled and neurodivergent students and even more so if they are multiply marginalized.

Part III, Directions for Positive Change, finally shifts the focus from narratives of student experiences to distill some of the most critical needs for support that those narratives have identified, and examples of promising practices from the literature that have been or could be implemented to address those needs. Chapter 7 addresses strategies in this area for addressing student needs within the curriculum, including considerations around time flexibility, removing barriers to accommodations, assistive technologies, proactive outreach and intervention strategies, and mentoring and coaching programs. Chapter 8 looks instead at strategies for needs outside the curriculum, which include financial and career support, improving the campus social climate, facilitating student connections to social support networks, mental and physical health care, and skill-building and information support. Finally, the Conclusions revisit the larger core concerns that must be addressed in light of all of this information, including the urgency of improving higher education, given its benefits, and the need to trust students as our partners in this work, and to identify necessary directions for future action and research in this area.

As a final logistical note, this book primarily employs parenthetical citations in the text, in accordance with U.S. conventions of educational research and for speed and ease of referencing. Due to its nature as a broad literature review, however, there are areas where a large number of references are included to support a single point. Therefore, parenthetical citations are used when citing three or fewer references, but in cases where more than three references are included in a single citation, for readability these have been removed to footnotes.