

The Struggle You Can't See

Experiences of Neurodivergent and Invisibly
Disabled Students in Higher Education

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3. Institutional Systems, Disability Services, and the Tensions of Self-Advocacy and Disclosure

Many of the current systems and structures of higher education can be fundamentally hostile to neurodivergent students and those with invisible disabilities. At minimum, these students may be required to make decisions and compromises in order to navigate their education that other students will not need to make, and they will likely need to learn additional strategies and coping mechanisms not required by their peers. Even though the most successful invisibly disabled and neurodivergent students may find long-term benefit from overcoming these additional challenges, they still represent inequities in the amount of effort different students must expend in order to achieve the same outcomes. In many cases, whether students are able to succeed in spite of more roadblocks is only a matter of chance and personality, rather than diligence or desire to learn. A student's success may also be directly hampered by the inherent characteristics of their difference. Even when university staff, faculty, and administrators have the best intentions of students at heart, the underlying assumptions and bureaucratic structures of the university still sometimes disproportionately set up certain students for failure.

Student outcomes show the impact of these inequities. According to the National Center for Education Statistics, the percentage of first-time students with disabilities who leave undergraduate education without return in their first year was 25.1% as of 2012, as opposed to 13.5% with no disability; 35.4% of students with disabilities had left without return by their second year, as opposed to 22.4% with no disability (United States Department of Education, 2017). Furthermore, not all disabilities

are reported, and students who are neurodivergent or have chronic illness, traumatic brain injury, or psychiatric disabilities tend to self-report at lower rates than other disability types. It is likely that some of the attrition assigned to students with 'no disability' in fact includes more students from these categories. Students with mental illness have been found to graduate at lower rates than those without—although their persistence rate appears to be comparable with that of students with other disability types (Salzer, 2012; Koch et al., 2014). Students with learning disabilities are also more likely to experience various types of barriers to their success in higher education, and to report lower overall satisfaction with their postsecondary experiences (McGregor et al., 2018).

With all of this in mind, this chapter will begin the discussion of the higher education experiences of neurodivergent and invisibly disabled students by providing an overview of their experiences with navigating higher education institutions overall, and the tensions they encounter in having to employ self-advocacy and disclosure of their conditions in order to do so. Foregrounded in the first area will be three types of experience that emerge as particularly relevant for these students:

1. Overall experiences, shared across multiple categories, that increase the challenges of participating in higher education;
2. Experiences with making decisions about institution and curriculum; and
3. Experiences interacting with and making use of institutional disability services offices.

It should be noted that disability services offices and personnel, in particular, are of tremendous importance to disabled students' overall higher education experiences. These resources serve as disabled students' primary means of making any necessary adaptations to their courses and learning environment, and thus students' experiences with them are likely to significantly impact their overall experiences. Relatedly, this chapter will also delve into the frequently conflicting desires and pressures students experience around disclosing neurodivergence and disabilities, asking for help, and advocating for their own needs to university faculty and staff. These, too, tend to fall into three main categories:

1. Reluctance to disclose and to seek help for needs, and the reasons behind this;
2. Issues around diagnosis and categorization of students, and the frequent requirement of documentation in order to qualify for accommodations; and
3. The role that disability identity plays in support-seeking, as well as why it may be problematic for many of the students under discussion here.

Between all of these elements, it should become evident why seeking supports is not a simple matter for neurodivergent students and those with invisible disabilities, and why true equity in higher education experiences may not be possible without drastic systemic reform.

Overall Challenges in Navigating Higher Education

One single most common challenge emerges from student narratives across all categories of neurodiversity and invisible disability. This is that significant additional burdens of time, labor, emotional distress, or all three are required to meet the same expectations that neurotypical and nondisabled students do. These extra burdens can take a number of different forms, depending on the typical characteristics and challenges of a category of difference. Multiple categories under discussion here tend to involve factors that directly affect the pace at which students can complete academic work, such as differences in cognition, reading, and other information processing that make reading and writing more laborious.¹ Difficulty concentrating is also a commonly reported symptom across multiple categories, whether this is inherent to the student's type of difference, or a result of distracting physical or psychiatric symptoms; this also extends the time required to complete independent assignments (Simmeborn Fleischer, 2012; Wennås Brante, 2013; Hong, 2015). Fatigue is another commonly recurring symptom, particularly

1 Bush et al., 2011; Erten, 2011; Melara, 2012; Mullins & Preyde, 2013; Wennås Brante, 2013; Downing, 2014; Kreider et al., 2015; Stampoltzis et al., 2015; Timmerman & Mulvihill, 2015; Childers & Hux, 2016; Hughes et al., 2016; Lefler, Sacchetti, & Del Carlo, 2016; Ward & Webster, 2018; James et al., 2020; Jones, 2020; Maurer-Smolde et al., 2021; Thompson, 2021.

given the commonality of sleep disturbances across these categories, and may cause delays and slow the pace at which students can complete academic work (Hughes et al., 2016). Academic schedules may also be in conflict with medical treatment schedules, especially for students with chronic illnesses, resulting in students being forced to choose between missing course deadlines or delaying treatment (Schwenk et al., 2014; Hoffman et al., 2019). Given all of these unavoidable factors interfering with their work, students with ADHD, in particular, often report the frustrating sense that they are investing tremendous time and effort into their studies, but their academic results are not commensurate with that effort or in line with their expectations of themselves (Hubbard, 2011; Young, 2012).

Outside of the academic curriculum, however, neurodivergent students and those with invisible disabilities face other disproportionate demands on their time and effort. Another activity into which students may need to invest these resources is advocating for their own needs in terms of disability support, and navigating the process of qualifying for and obtaining institutional accommodations (Strnadová et al., 2015; Lizotte, 2018). As Hollins and Foley (2013) point out, even if help is available to surmount barriers in the academic environment, having to seek out that help also takes additional work, by students who are already being required to invest more time and effort into their education than others. Especially for autistic students and those with some types of chronic illness, it may take more than usual effort to manage activities of daily living as well, and, far more often than with academic challenges, students are unwilling or unable to obtain institutional support for managing these types of need.² Attending higher education may be the first time in a student's life that they have been required to manage their own daily living needs independently, and making that (often unsupported) adjustment on top of meeting new academic requirements can be extremely overwhelming (Schwenk et al., 2014; Cage & Howes, 2020). In at least one study, students with ADHD report finding the already excessive demands on their time increased further by the need to hold a job while attending school, which is likely a factor in other categories as well (Melara, 2012). Students with chronic illnesses, on top

2 Simmeborn Fleischer, 2012; Cullen, 2013; Simmeborn Fleischer et al., 2013; Kreider et al., 2015; Toor et al., 2016; Anderson et al., 2017; LeGary, 2017; Hoffman et al., 2019.

of other time concerns, report needing to budget time into their schedules for the possibility of medical emergencies (Toller & Farrimond, 2021). Even if students may be able to achieve a balance between other factors and their academic lives, achieving and maintaining that balance is also a task that requires an investment of time and effort (Colclough, 2018; Spencer et al., 2018; Hoffman et al., 2019).

As a result of these outsized demands on their time and their physical and mental energy, many of these students are required to make adjustments and sacrifices in order to be successful academically, often to the significant detriment of their overall quality of life. Students across numerous studies and categories report having to forego social engagement, personal lives, and extracurricular activities simply to be able to keep up with the academic demands on their time.³ Students in multiple studies describe taking even more extra time to work outside of classes and assignments, in order to try to keep from falling behind classmates, by reviewing lectures and other course materials, viewing instructional videos online, and other compensatory strategies (Pino & Mortari, 2014; MacCullagh et al., 2016). Although group work in classes can be very beneficial and desirable for students in several of these categories, a number of studies have observed that group projects can also be a major source of anxiety and discomfort for these students, because of the difficulties the extra demands on their time present in keeping pace with their fellow group members.⁴ In a number of very real ways, the extra work that higher education demands from neurodivergent and invisibly disabled students not only increases their time pressures and stress, it prevents them from accessing the full college and university experience that is available to their nondisabled and neurotypical peers.

Institution and Curriculum

Another common experience reported by many disabled and neurodivergent students is that inequity begins for them from the very first step in the higher education process: choosing an institution to

3 Randolph, 2012; Couzens et al., 2015; Kreider et al., 2015; Lambert & Dryer, 2018; Ward & Webster, 2018; Gurbuz et al., 2019; Harn et al., 2019; Krumpelman & Hord, 2021.

4 Kreider et al., 2015; Pirttimaa et al., 2015; Stampoltzis et al., 2015; Giroux et al., 2020.

attend. Multiple studies have found that, depending on the nature of a student's specific needs, their choices of higher education institution may be driven by the relative availability of supports at a particular institution—or lack thereof at another.⁵ This limitation was particularly frequently mentioned in studies of autistic students, although students with ADHD, TBI, and other considerations also reported making the same types of decision. Autistic students have specifically mentioned that they would advise similar students to choose an institution and discipline based on their needs as well as their interests, and also found other features of certain campuses to potentially influence their choices, such as small size or proximity to home (Anderson et al., 2020). Campus size and proximity to home were also common criteria for institutions chosen by students with other types of impairments (Flowers, 2012; Davis, 2019), and the layout of a campus, distances, and transportation issues have all been noted as significant potential barriers for students, particularly those with chronic illnesses (Redpath et al., 2013). While some of these elements may also be factors in college or university choice for nondisabled and neurotypical students, many neurodivergent and invisibly disabled students have to consider them as make-or-break factors in their ability to succeed in higher education, not merely as matters of preference. Moreover, having to calculate for institutions' widely varying levels of disability support and accessibility limits students' ability to choose their institutions based on other factors, like academic, social, and extracurricular interests.

Similar constraints apply to students' choices regarding academics. Across many studies, students report needing to reduce their own academic self-expectations in various ways to be able to advance through higher education, often at the cost of their interests and goals. Students may find they need to take a reduced courseload or only take one course at a time (Bush et al., 2011; Schindler & Kietz, 2013; Kain et al., 2019), change their course content, such as avoiding certain topics or intensive reading and writing requirements (Schindler & Kietz, 2013; Pirttimaa et al., 2015), or move to less demanding programs altogether.⁶

5 Flowers, 2012; Redpath et al., 2013; Accardo et al., 2019b; Davis, 2019; Anderson et al., 2020.

6 Childers & Hux, 2016; Anderson et al., 2018; Leopold et al., 2019; Anderson et al., 2020; Toller & Farrimond, 2021.

It should be stressed that, overall, these changes are not made due to their level of academic aptitude or diligence, but because of unavoidable factors inherent in the lives of the students in question. Autistic students in Anderson et al. (2018) who reported leaving their academic unit, for example, did so not because of a lack of affinity for the material, but explicitly because they were not consistently provided with the supports they needed to complete their work: they found that necessary accommodations were not available or simply not provided, they encountered negative experiences in trying to secure accommodations, or university staff failed to follow up to ensure their needs were actually met. As one student succinctly described their experience, “[Got] my reasonable adjustment document on Friday of week 12 in a 13-week semester.” (Anderson et al., 2018)

Disability Support Services

Studies have repeatedly found correlations between neurodivergent and invisibly disabled students’ use of supports and accommodations and their academic success. Most commonly, access to accommodations has been found to be significantly correlated to persistence to graduation, based on quantitative data and systematic reviews of literature.⁷ Additionally, across many interview studies, there is an overwhelming consensus among students themselves that accommodations are beneficial and support their academic success,⁸ although care and appropriateness in implementation does affect the perceived helpfulness of the accommodations.⁹

As a result of these factors, it is concerning that, as quantitative studies and literature reviews have also shown, relatively few of these same students report accessing disability services and accommodations.

7 Pingry O’Neill et al., 2012; Koch et al., 2014; Kutscher & Tuckwiller, 2019; Clouder et al., 2020; Newman et al., 2021.

8 Erten, 2011; Heiney, 2011; Zafran et al., 2011; Flowers, 2012; Melara, 2012; Randolph, 2012; Mullins & Preyde, 2013; Rutherford, 2013; Ennals et al., 2015; Kreider et al., 2015; Cai & Richdale, 2016; Childers & Hux, 2016; Toor et al., 2016; Casement et al., 2017; Pitt & Soni, 2017; Sarrett, 2017; Berry, 2018; Kent et al., 2018; Lightfoot et al., 2018; Lizotte, 2018; Accardo et al., 2019b; Kain et al., 2019; Anderson et al., 2020; Thompson, 2021.

9 Hadley & Satterfield, 2013; Van Hees et al., 2015; Hoffman et al., 2019; Scheef et al., 2019.

Koch et al. (2014) found that less than 10% of students with psychiatric disabilities reported using accommodations, with 15% indicating that they needed extended time accommodations but had not received them. Newman and Madaus (2015) found that among students with any disability, while 95% had received at least one accommodation at the level of secondary schooling, only 23% had at the postsecondary level. McGregor et al. (2018) found that only around 33% of students with learning disabilities received accommodations. Barber and Williams (2021) found that less than half of women students with chronic illness surveyed had received accommodations, and in a literature review on autistic students, Krumpelman and Hord (2021) found that students frequently reported not using academic supports even when they were available. Furthermore, across multiple cases and categories, interview studies frequently found that neurodivergent and invisibly disabled students report not using disability services or accommodations, not having or seeking access to them, or even actively resisting the idea of using them.¹⁰

What stands in the way of students' receiving any accommodations, or all of the accommodations that they truly need? One of the most significant barriers across studies is that, for a variety of reasons, students are reluctant to seek out assistance, to disclose information about their needs, to identify themselves as disabled, or all of these. The issue of disclosure and help-seeking is a complex one that has been discussed broadly across the literature, and will be investigated in greater detail in the following sections. Many other barriers exist, however, that also prevent students from receiving the help they need from disability support services. One that also recurs frequently is lack of awareness: students either do not know that disability services are available, or do not know they would qualify.¹¹ Even when students are aware of accommodations, furthermore, the processes of qualifying for and obtaining them is often confusing and

10 Bush et al., 2011; Heiney, 2011; Melara, 2012; Tarallo, 2012; Downing, 2014; Ness et al., 2014; Kent, 2015; Sayman, 2015; Gottschall & Young, 2017; Anderson et al., 2018; Kent et al., 2018; Serry et al., 2018; Clouder et al., 2020; Barber & Williams, 2021; Maurer-Smolder et al., 2021.

11 Heiney, 2011; Demery et al., 2012; Cullen, 2013; Markoulakis & Kirsh, 2013; McEwan & Downie, 2013; Redpath et al., 2013; Rutherford, 2013; Kreider et al., 2015; Giroux et al., 2016; Goodman, 2017; Serry et al., 2018; Anderson et al., 2020; Owens, 2020; Maurer-Smolder et al., 2021; Pfeifer et al., 2021.

unfamiliar, which can discourage students from seeking supports from the outset, feeling that trying to muddle through unsupported would be easier than expending even more time and effort for uncertain returns.¹² Many students may use other campus supports rather than trying to navigate all the hurdles of obtaining accommodations, even when accommodations are demonstrably helpful (Richardson, 2021). Even if students do pursue disability services support, furthermore, many report difficulties with actually accessing accommodations,¹³ including being told they do not qualify for services (Winberg et al., 2019) or having requests denied (J.B. Roberts et al., 2011). Complex bureaucratic procedures sometimes lead to significant delays, inconsistent application, or complete failures to provide accommodations even when they should theoretically be granted.¹⁴

In navigating these processes, some students also report negative experiences with disability services staff in general (Heiney, 2011; Hong, 2015; Lightfoot et al., 2018). Specifically, some found even these staff treated them with suspicion, disbelief, and other negative attitudes (Cai & Richdale, 2016; Spencer et al., 2018), or did not seem to have sufficient understanding of their individual conditions and needs.¹⁵ These experiences are by no means universal, and many other students report more positive experiences and impressions of disability services staff (Lightfoot et al., 2018; Zeedyk et al., 2019). If students do have negative experiences with the same staff members who are most meant to understand and assist them, however, the impact on students' well-being and receipt of needed services has the potential to be devastating, as Heiney (2011) also notes. As will be discussed in later chapters, help-seeking can be particularly difficult and vulnerable for autistic students and those with psychiatric disabilities, and even one negative experience could dramatically decrease these students' likelihood of persisting until their needs are met (Demery et al., 2012). As Toller and Farrimond

12 J.B. Roberts et al., 2011; Mullins & Preyde, 2013; Strnadová et al., 2015; Childers & Hux, 2016; Sarrett, 2017; Berry, 2018; Lightfoot et al., 2018; Spencer et al., 2018; Winberg et al., 2019.

13 Habib et al., 2012; Koch et al., 2014; MacCullagh et al., 2016; Lightfoot et al., 2018; Maurer-Smolde et al., 2021.

14 Melara, 2012; Redpath et al., 2013; Stampoltzis et al., 2015; Bunch, 2016; Cai & Richdale, 2016; Sarrett, 2017; Anderson et al., 2018.

15 Lefler et al., 2016; Serry et al., 2018; Leopold et al., 2019; Barber & Williams, 2021.

(2021) observe, what students experience from disability services offices is sometimes a matter of luck in terms of which individual staff members work with them, and, when true, this is cause for serious concern about the equity of the process. As Hubbard (2011) notes, disability services offices are also likely to be underfunded or understaffed overall, to the detriment of the ability of even the best staff to meet students' needs.

Even when accommodations are successfully provided, meanwhile, in practice they may prove to be less helpful than students hope. Across many studies, students report receiving accommodations that were insufficient or poorly suited to their actual needs.¹⁶ As Redpath et al. (2013) notes, sometimes the workarounds implemented to accommodate disabled students introduce additional complications that could have been avoided by simple flexibility in how to complete coursework, such as when a specialized testing environment is provided that creates additional barriers for a student, rather than allowing the student to be evaluated by other means than a test. The ways that accommodations are implemented can also place still more burdens on the students receiving them, such as requiring students to approach peers as potential note-takers rather than having note-takers selected for them (Hadley, 2017), or the frequent requirement that students present and negotiate their accommodation needs with faculty personally (Hoffman et al., 2019). Additionally, support outside of the academic curriculum may be difficult or impossible to obtain, either in students' perception or in fact.¹⁷ In short, as a student in Erten (2011) observes with regard to accommodations: 'It is just so funny that it is perceived as privilege, when even it isn't equal' (p. 108). The many difficulties and shortcomings of accommodations alone should dispel the impression that these represent an 'unfair advantage' for disabled students—and yet that stigma persists, and creates another burden for students who do manage to obtain accommodations to bear.

16 Hubbard, 2011; Cullen, 2013; Stein, 2013; Gelbar et al., 2015; Hong, 2015; Cai & Richdale, 2016; Giroux et al., 2016; Lefler et al., 2016; Gottschall & Young, 2017; Lightfoot et al., 2018; Hoffman et al., 2019; Zeedyk et al., 2019; Barber & Williams, 2021; Maurer-Smolder et al., 2021; Thompson, 2021; Toller & Farrimond, 2021.

17 Cullen, 2013; Toor et al., 2016; Anderson & Butt, 2017; Clouder et al., 2020; Krumpelman & Hord, 2021.

Issues around Disclosure and Help-Seeking

Regardless of how much support they may need, students are often unwilling to disclose those needs to university administrators, faculty, and staff, even to obtain formal accommodations and other services. This is one of the most commonly recurring elements of the interviews and surveys examined. In some cases, a study will simply note the student's unwillingness or failure to obtain supports that would require acknowledgement of their disability or neurodivergence, with few details about reasoning provided, beyond that students were uncomfortable doing so.¹⁸

When there is information on why students choose not to disclose or seek help, however, certain reasons seem to recur over and over. By far the most common, across multiple studies and categories, is that students are afraid of being stigmatized if they disclose, either because they anticipate stigma, they have internalized stigma, or in many cases, because they have actually experienced stigma in the past.¹⁹ In some cases, negative and stigmatizing experiences with peers have left lasting impressions on students, preventing or delaying them from seeking academic support (Winberg et al., 2019; Lett et al., 2020; Pfeifer et al., 2021). In other cases, faculty and staff interactions may have already borne out students' fear of stigma from authority figures in these roles. These concerns will be addressed in greater detail in Chapter 4. Some students hold the related fear that they will be disbelieved about their needs, often due to past experience (Bolourian et al., 2018; Spencer et al., 2018). The invisible nature of the categories presented here tends to contribute to students' unmet needs and to their being misunderstood.²⁰

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- 18 Demery et al., 2012; Anderson et al., 2018; Kent et al., 2018; Hoffman et al., 2019; Leopold et al., 2019; Owens, 2020; Barber & Williams, 2021; Krumpelman & Hord, 2021.
- 19 J.B. Roberts et al., 2011; Markoulakis & Kirsh, 2013; Mullins & Preyde, 2013; Redpath et al., 2013; Stein, 2013; Pino & Mortari, 2014; Hong, 2015; Pirttimaa, 2015; Timmerman & Mulvihill, 2015; Van Hees et al., 2015; Cai & Richdale, 2016; Lefler et al., 2016; Sokal & Desjardins, 2016; Toor et al., 2016; Anderson et al., 2017; Bolourian et al., 2018; Cox et al., 2017; Goodman, 2017; Lightfoot et al., 2018; Serry et al., 2018; Ward & Webster, 2018; Adams et al., 2019; Kain et al., 2019; Winberg et al., 2019; Clouder et al., 2020; Giroux et al., 2020; Grimes et al., 2020; James et al., 2020; Miller et al., 2020; Maurer-Smolder et al., 2021; Richardson, 2021.
- 20 Erten, 2011; Childers & Hux, 2016; Giroux et al., 2016; Anderson et al., 2018; Spencer et al., 2018; Zeedyk, 2019.

Another frequently recurring barrier to student disclosure and help-seeking is that students may feel that they are not needy or 'deserving' enough to merit support, and they may see (or feel that others see) accommodations as unfair advantages.²¹ A number of studies demonstrate that students' fear of this perception is justified: Giroux et al. (2016) noted negative attitudes toward accommodations and even toward ill students when surveying faculty, and in multiple studies students recount lived experiences with peers who were resentful or skeptical of their accommodations and medications (particularly in the case of medication for ADHD) as perceived unfair advantages.²² Even neurodivergent and disabled students themselves have clearly internalized these ideas in several studies, framing their own actual or potential accommodations as undeserved 'handouts,' which they may feel potentially compromise the worth of their education and degrees.²³ In one student's words:

I have found it really difficult asking for help. I hate it. I guess it's just something psychological that I need to get past. I'll think, 'Why should I be advantaged?' 'No, no, no, you can't do that. It's wrong!' 'I'm cheating by taking this extension'. (Ward & Webster, 2018, p. 387)

Cameron & Billington (2017) particularly and usefully point out the neoliberal foundations of these ideas, rooted in a valorization of need-blind 'equality' over genuine equity in education—which many students have likely internalized from the pervasiveness of similar framings in their educational and social environments.

Similarly, another major reason that students do not disclose accommodation needs is their desire for independence, and the misplaced sense that institutional support would constitute undesirable dependence. In many interviews, students identified the desire to be independent or to succeed in college 'on their own' as a reason

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- 21 J.B. Roberts et al., 2011; Markoulakis & Kirsh, 2013; Mullins & Preyde, 2013; Pino & Mortari, 2014; Couzens et al., 2015; Timmerman & Mulvihill, 2015; Spencer et al., 2018; Maurer-Smolder et al., 2021.
- 22 Young, 2012; Mullins & Preyde, 2013; Kreider et al., 2015; Gottschall & Young, 2017; Pfeifer et al., 2021.
- 23 Sayman, 2015; Childers & Hux, 2016; Lefler et al., 2016; Cameron & Billington, 2017; James et al., 2020.

for not seeking accommodations.²⁴ In some cases, students even described specifically wanting to complete their work without the use of supports,²⁵ or expressed that they equated the use of supports with dependence (MacCullagh et al., 2016; Sokal & Desjardins, 2016) or even ‘cheating’ (Sayman, 2015). Cameron and Billington (2017), along with Heiney (2011), again note the influence of neoliberal attitudes on this construction, in which students position individualism as paramount and themselves as solely responsible for their own success or failure in college. They also note that this construction therefore positions students who are less successful or have greater need as simply less hard-working or deserving, and fails to recognize the potential for solidarity between students who need support. It is not difficult to see how such ideas have infiltrated students’ own self-understandings, either, when examining the framings sometimes employed even by the authors of these studies. Bush et al. (2011) and Hadley and Satterfield (2013), for example, seem particularly fixated on the need for students to be independent, and the concern that faculty and staff will ‘over-accommodate’ them—which is anything but borne out by the literature overall. Hadley (2017) even goes so far as to characterize a dyslexic and dysgraphic student’s expressed desire for writing support—a very common academic support for disabled and nondisabled students alike—as ‘dependence’ (p. 24). With even some of their allies in academia configuring their support needs in these terms, it is not at all surprising that many students fear support would reflect on them poorly as independent learners.

A related barrier that prevents students from disclosing needs or seeking help is feeling embarrassment, shame, secrecy, or related emotions around their neurodivergence or disability (Hubbard, 2011; Lefler et al., 2016; Sokal & Desjardins, 2016). Likely due to heightened social stigma around psychiatric disabilities, this problem is mentioned especially frequently in the narratives of students with these conditions.²⁶ These students have been found to have a particular desire for privacy in academic services, including library services (Sokal & Desjardins,

24 Kirwan & Leather, 2011; Tarallo, 2012; Timmerman & Mulvihill, 2015; MacCullagh et al., 2016; Anderson et al., 2017; Bolourian et al., 2018; Serry et al., 2018; Anderson et al., 2020; Miller et al., 2020.

25 Melara, 2012; Ness et al., 2014; Kent et al., 2018; Adams et al., 2019.

26 Hubbard, 2011; Demery et al., 2012; Stein, 2013; Sokal & Desjardins, 2016.

2016; Pionke, 2017), and to be particularly unlikely to disclose their disabilities compared to students with other disabilities (Kent, 2015). Some students also note discomfort with seeking out disability services due to the possibility of hypervisibility or drawing unwanted attention to themselves (Mullins & Preyde, 2013), which may also in some cases be related to these concerns.

The need for self-advocacy that the support-seeking process demands is yet another significant barrier, often noted across the literature. A number of studies have found that self-advocacy skills and capacity are quite unevenly distributed across their student participants, with some students experiencing the need to self-advocate as a major struggle.²⁷ This is noted in several studies of autistic students, even when students are self-aware of the support that they need (Ward & Webster, 2018; Krumpelman & Hord, 2021). Lack of advocacy skills has even been found to be a major factor in non-completion for autistic students (Anderson et al., 2020). It is true that the capacity for self-advocacy is a positive and valuable skill, and many student narratives explicitly recognize this fact.²⁸ In a number of studies, furthermore, students found that their help-seeking and self-advocacy skills developed over time, as they increased their understanding of themselves and of what help was available.²⁹ Entering students seldom receive any explicit training in this skill, however, and as noted at the beginning of this chapter, a third of all disabled students leave college without return by their second year, meaning that for many, this growth never has time to occur. It is to their benefit when students do develop self-advocacy skills, but for these skills to be required in order to succeed in college at all is problematic to say the least, when they are so challenging for many and slow to develop. It is equally problematic to place the onus on disabled students to fight and persist just to access what they are legally entitled to, rather than to take responsibility for reducing the barriers that make self-advocacy so necessary.

27 Hubbard, 2011; Childers & Hux, 2016; Ward & Webster, 2018; Davis, 2019; Krumpelman & Hord, 2021.

28 Hubbard, 2011; Melara, 2012; Strnadova et al., 2015; Berry, 2018; Lightfoot et al., 2018; MacLeod et al., 2018; Accardo et al., 2019b; Davis, 2019.

29 Tarallo, 2012; Sayman, 2015; Childers & Hux, 2016; Lux, 2016; Berry, 2018; Bolourian et al., 2018; Davis, 2019; Harn et al., 2019.

Finally, even if students are willing to overcome all of these potential barriers, they often do not believe the supports or accommodations they would receive would be helpful.³⁰ As discussed above, this concern is in many cases justified, with the available institutional accommodations proving insufficient or ill-suited to the student's need. If students do not feel they can be confident that their experience with disability services will be sufficiently private or respectful of their needs, nor that it will result in support that will actually benefit them and address those needs, it is entirely reasonable that they may not choose to push past the many barriers and seek formal assistance. Instead, as reported in a number of studies, they are more likely to attempt to compensate on their own for their additional pressures, and self-disclose selectively only to specific course faculty or when their need is the greatest.³¹

Diagnosis and Categorization

Another complicating factor of seeking accommodations is that students are generally required to provide evidence of formal diagnosis with a disability in order to qualify. Obtaining a diagnosis from a medical professional, however, is not always a simple matter, especially when it comes to neurodivergence and invisible disabilities. Simply undergoing the medical processes required can be a significant barrier in terms of time, effort, and financial cost.³² As noted by Winberg et al. (2019), the categories under discussion here also tend to present in highly diverse ways, meaning that a student's legitimate impairments may go misdiagnosed or undiagnosed because they vary from those of others with the same condition. Even when students are diagnosed, autistic students may be particularly likely to resist their diagnosis (Cox et al., 2021), while some students with ADHD and other neurodivergence classified as 'learning disabilities' may experience diagnosis as profoundly negative, even detrimental in itself (Lux et al., 2016)—although others may find it comes as a relief and an explanation for ongoing issues

30 Heiney, 2011; Tarallo, 2012; Anderson et al., 2017; Kent et al., 2018; Serry et al., 2018.

31 Melara, 2012; Schwenk et al., 2014; Barber & Williams, 2021; Turosak & Siwierka, 2021.

32 Cai & Richdale, 2016; Lightfoot et al., 2018; Anderson et al., 2020; Barber & Williams, 2021; Pfeifer et al., 2021; Toller & Farrimond, 2021.

(Young, 2012). In any case, the experience has a significant emotional as well as practical impact, and is frequently reported as a major hurdle to pass before receiving support.

Compounding this challenge is the fact that students may or may not have received a diagnosis prior to college at all, and may not even be aware that there is anything to diagnose. Late diagnosis is common in the categories under discussion here, relative to other types of disability.³³ In Lizotte (2018) and Cage and Howes (2020), multiple student participants had not even been diagnosed until after finishing college. Students with psychiatric disabilities, in particular, have been found to be far less likely than those with other types of disabilities to be diagnosed during primary or secondary education, leading to lack of supports, lack of knowledge of their own needs, and sometimes not even realizing that they have unique needs that could be met (Hubbard, 2011; McEwan & Downie, 2013; Stein, 2013). Diagnosis can also be particularly delayed for autistic women, due to stereotypical association of autistic traits with men, and gendered differences in how autism tends to manifest (Cage & Howes, 2020; Krumpelman & Hord, 2021). This not only impacts students in higher education, but is also likely to have impacted their previous schooling experiences, affecting their level of academic performance, their resulting preparation for college, and even their psychological well-being. Earlier diagnosis has been linked to more positive self-acceptance and academic success (Pitt & Soni, 2017; Cipolla, 2018; Lightfoot et al., 2018) and greater readiness for managing invisible physical illness (Schwenk et al., 2014). Some autistic students specifically report that experiencing late diagnosis was a barrier to their success (Accardo et al., 2019b). Furthermore, students who were not diagnosed prior to reaching higher education consequently did not have documentation or allotted accommodations in their secondary schooling, meaning they did not enter college with plans or expectations for similar supports, or foreknowledge that they might need to seek out disability services (Hubbard, 2011; Flowers, 2012; Sarrett, 2017). Some students report that these disadvantages had made them feel they were not able to fully access and benefit from their primary and secondary education (Hubbard, 2011), and some had experienced resulting lack of self-understanding and low self-esteem, or had even been told they

33 Hubbard, 2011; Young, 2012; Doikou-Avliidou, 2015; Sarrett, 2017.

were 'stupid' rather than working at a genuine disadvantage (Hubbard, 2011; Sarrett, 2017). While higher education faculty and staff cannot retroactively remedy these past experiences, they should certainly take them into consideration as factors in the support these students may need, and the challenges they may face.

Disability Identity

Related to the issue of diagnosis is the issue of disability identity, and how it affects students' support-seeking, self-advocacy, and overall well-being. In student narratives in a number of studies, the idea of using accommodations was in tension with students' self-conceptions as either not disabled at all, or not having significant need compared to others with disabilities.³⁴ In fact, students in several studies specifically report not seeking out disability services because they did not consider themselves to be disabled (Downing, 2014; Timmerman & Mulvihill, 2015; Goodman, 2017). Students in the categories discussed here are, across multiple studies, frequently reluctant to identify themselves as disabled, or are resistant to that categorization.³⁵ This is an unfortunate fact in many respects, because, in numerous studies, positive disability identity has been linked to greater academic success, and increased likelihood of accessing academic supports and developing effective coping strategies (Erten, 2011; Kreider et al., 2015; Clouder et al., 2020). Stronger disability identity has also been cited as mitigating negative impacts on academic self-esteem and self-confidence that students experience as a result of their learning difficulties (Brandt & McIntyre, 2016).

Many neurodivergent and invisibly disabled students, however, do not feel able to claim the disability identity that would help support them in these ways. Lower disability identity and more ambivalence around one's diagnosis are especially frequently reported across studies of autistic students,³⁶ and of those with psychiatric disabilities (Kent,

34 Mullins & Preyde, 2013; Timmerman & Mulvihill, 2015; Cox et al., 2017; Spencer et al., 2018.

35 Heiney, 2011; Hubbard, 2011; Melara, 2012; Kreider et al., 2015; Sayman, 2015; Goodman, 2017; Clouder et al., 2020; James et al., 2020; Cox et al., 2021.

36 Simmeborn Fleischer, 2012; Downing, 2014; Sayman, 2015; MacLeod et al., 2018; Cox et al., 2021.

2015; Sayman, 2015; Goodman, 2017). It is worth noting, however, that as with self-advocacy skills, for many students disability identity tends to develop over time. During their time in college, students across a number of studies found that they gradually embraced a disability identity over time, integrating an increasing understanding of their own characteristics and needs into their sense of self.³⁷ Requiring students to self-report disabilities to receive institutional support, however, means that students' success may directly depend on their self-identification as disabled—which renders even a temporary resistance to this identity problematic for students, especially in the earlier, foundational years of higher education.

As Spencer et al. (2018) note, students all too often seem to find themselves caught between not wanting to identify as ill or disabled, but feeling compelled to do so nonetheless in order to be believed by faculty and staff, and to receive the supports that they need. The status of 'healthy' is valorized and prioritized socially in general, and chronically ill students internalize those values, making them seek to construct their own identity as 'healthy' and the traits that disable them as incidental. This makes the seeking of supports not only a significant practical challenge, but a potential identity crisis as well. It also seems apparent, given other components of the narratives of neurodivergent and invisibly disabled students, that a great deal of their resistance to a disability identity is due to the justified fear of the stigma and discrimination faced by people with that identity.

Whether a student identifies as disabled or not is a personal and individual matter, but it is of serious concern if students eschew this identity primarily because of how they may be treated because of it, and to their cost. It is also of note that when disability is stigmatized in higher education, and as a result students are unwilling to identify as disabled to seek support, this directly serves the interests of institutions reluctant to invest the time and effort needed to improve services for disabled students. I do not mean to suggest that university faculty and staff, when they do so, cause students to feel judged, ashamed, and belittled for disclosing disabilities in order to intentionally prevent those students from seeking disability support services from the university.

37 (Hubbard, 2011; Zafran et al., 2011; Ennals et al., 2015; Lux, 2016; Bolourian et al., 2018; Cage & Howes, 2020.

I do believe, however, that if university systems are set up to provide these types of services only reluctantly, this cannot help but influence the attitudes and behavior of many university employees.

Summary and Conclusions

While the campus environment may not hinder invisibly disabled and neurodivergent students as obviously as it can other disabled students, such as those who use mobility devices or have impairments of perception, their access to higher education is nevertheless definitively more limited and more difficult than that of nondisabled and neurotypical students. Students across all categories under discussion here experience substantially outsized demands on their time and energy in higher education, often to the point of having to limit or entirely forego non-academic activities. Their choices of course content, course modality, department and program, and even institution are likely to be limited artificially by which choice they feel will be able to meet their needs, rather than being freely made based on their academic interests and personal preferences. Furthermore, while many neurodivergent and invisibly disabled students may encounter barriers in the process of seeking accommodations, many others opt not to identify themselves or pursue support at all. This is not an irrational decision on the part of students: it is informed by their experiences of how they may be treated if they disclose their needs, and by prevailing attitudes about who is and is not 'deserving' of support, how support is equated to dependence, and how needing certain types of support is perceived as shameful. Even if they should decide to conquer all of these concerns, they are forced to advocate for themselves aggressively and persistently to receive support, which many are unequipped to do. It is also often unclear to them what support is available and how it would be helpful, causing them to lack confidence that this substantial effort would be worthwhile. Compounding these difficulties are the facts that invisibly disabled and neurodivergent students may not have received a diagnosis at all prior to college, or even during college, and may not be aware of what their needs are, let alone able to provide evidence of diagnosis to qualify for accommodations. Even if they have been diagnosed, they may feel significant ambivalence toward or even

resist the diagnosis, and in many cases may not identify as disabled at all, making them unlikely to seek out supports that are identified as being for students with disabilities. The ability of students to manage all of these factors does appear to increase over time, but when more than one-third of students with disabilities permanently withdraw from college within their first two years, it is clear that many students are not able to persist long enough under these conditions for that growth to occur.

It is a choice to frame higher education this way. It is a choice to offer a singular educational experience, dictated by the judgment of faculty and staff, the requirements of which students must either meet as they are and unaided, or by requesting workarounds that will help them overcome the parts of the standard mold they find most insurmountable—and then require them to offer justification and proof of why they need and deserve even that much flexibility. Like students' choice to avoid disclosing their needs and asking for help, it is not an irrational choice, and there are practical, philosophical, and historical reasons for these procedures to be in place. Like many students' choices described here, though, it is also not a choice that results in equitable educational experiences. The neurodivergent and invisibly disabled students who are able to succeed in this environment are not definitionally those who are most academically capable, but those who are most fortunate. Students can succeed if, by chance, they happen to be able to persist through bureaucratic systems, identify and make the case for their own needs, brave the social stigma around those needs, and access medical treatment and diagnosis—or else exert all of the extra time and effort required to compensate for those needs without any formal support at all. Those unable to do either of these things will not even have the opportunity to prove their capability for academic work and learning. They will fail at the format.

This is not the only way that supporting disabled students in higher education could work. Pursuing a more equitable environment for neurodivergent and invisibly disabled students can begin with reframing how support is made available, from 'students who need it can get help on request' to proactively seeking on the university side to eliminate barriers, increase flexibility, and make supports independently available for all students, regardless of their needs or how they self-identify.

These are the principles behind Universal Design, whether in the form of Universal Design for Learning (UDL) or other forms of design. The more an institution's culture is able to shift in this direction, the less any given student's self-advocacy skills, diagnosis, or disability identity will matter to their ability to be successful in higher education. It is not a simple matter to shift the design of systems and policies this way, but it is a shift from which every part of the institution can benefit—including, as will be discussed next, the classroom environment itself.

