# The Struggle You Can't See

Experiences of Neurodivergent and Invisibly Disabled Students in Higher Education

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Cover image: A stack of books with a ladder leaning against it, September 23, 2023, Unsplash+ in collaboration with 8machine, licensed under the Unsplash+ License, https://unsplash.com/photos/a-stack-of-books-with-a-ladder-leaning-against-it-KIqVxfgwx-w Cover design: Jeevanjot Kaur Nagpal Just as students' experiences and recommendations have suggested possible areas for improvement of their academic lives, the same is true of their lives on campus outside of class. As discussed in previous chapters, the campus environment encompasses many important aspects of students' lives beyond just the curriculum, especially for residential students. Not only are a student's social life, material circumstances, health, and self-determination skills also important, but they can have direct impacts on academic success, as has been demonstrated in previous chapters. Fortunately, a number of examples of promising practice are available that address these areas as well.

The strategies for improving students' co-curricular lives that will be discussed in this chapter can be organized into these categories:

- 1. Financial and career support resources for disabled students;
- 2. Improving institutional social climate and the attitudes of peers, faculty, and staff;
- 3. Strategies for making social support networks more available for all students, including those who struggle to form those networks organically;
- 4. Campus mental and physical health care services; and
- 5. Strategies to develop critical skills and information awareness for students.

As in the previous chapter, some of these areas of practice have been more fully developed than others. In each case, however, there are promising starting points for meeting the needs of the students in these categories, and addressing some of the common problems that they describe.

# Financial and Career Support

#### Financial Support

As has been alluded to in previous chapters, when students are forced to make their own individual arrangements to navigate a disabling environment, that demand carries substantial, additional, and hidden material costs-which are not factored into financial aid calculations (Eichelberger et al., 2017). Extra financial costs associated with supports for academic study can be a significant added barrier and source of stress for students in college.<sup>1</sup> In particular, in Canada, students with nonapparent disabilities have been found to receive less federal funding on average than students with other types of disability, and chronically ill students have been found to carry the most debt from higher education (Chambers et al., 2013). Students with financial aid packages can find these jeopardized if they are forced to finish higher education at a slower pace than others, or if their academic performance dips, for example due to a sudden flare of symptoms or mental health crisis. Higher education can be prohibitively expensive for many students, particularly in the U.S. and for those from marginalized communities, but there are particular challenges for disabled and neurodivergent students that make material aid for college especially critical. Financial support is extremely valuable when available, as many students have noted.<sup>2</sup>

Beyond financial aid opportunities that are available to all students, there are a few sources of funding for disabled students specifically, although each of these can present their own challenges. In the U.S., financial aid adjustments for disabled students can be available by request, but as with many other services around higher education, students may not be aware of these or willing to seek them out if they are (Perlow et al., 2021). Likewise, the U.S. and Canada also have a number of national by-application grants and scholarships from various independent funders, but, like navigating the accommodations process in college, these put a medicalized burden of proof on students in applying, for no guarantee of any return (Mou & Albagmi, 2020).

<sup>1</sup> Lambert & Dryer, 2018; Lightfoot et al., 2018; Accardo et al., 2019b; Anderson et al., 2020; Barber & Williams, 2021.

<sup>2</sup> Rutherford, 2013; Schindler & Kietz, 2013; Ravert et al., 2017; Jones, 2020.

Tuition benefits for service member and veteran students are also offered in the U.S., although policies and implementation can lead to varying success rates (Hitt et al., 2015). In other nations, there are examples of similar awards as well, with varying levels of remuneration and barriers to entry. The United Kingdom offers disabled student allowances, which can be used to pay for technology and other forms of learning support (Eseadi, 2023), although this aid has been scaled back in recent years by changes like requiring students to make a certain level of contribution before receiving aid (Disabled Students Allowances, 2018). In Brazil, the University for All Program, or ProUni, provides full and partial scholarships to students from underrepresented groups, including disabled students, although it also requires an application process and has significant requirements in terms of income level, academic performance, and verification (de Azevedo Pedrosa et al., 2015).

Individual institutions may also offer financial support for disabled students, although this is by no means universal. Investigating financial aid information online for the U.S. universities with the top ten highest endowments-arguably those best positioned to offer financial support to students who need it most-reveals that three of these appear to offer scholarships for disabled students: the University of Pennsylvania, Texas A&M University, and the University of Michigan. University of Michigan simply identifies the amount of its disability funding as 'at least \$1000,' while University of Pennsylvania and Texas A&M each offer a number of scholarships in this area, the former without specified amounts and the latter tending to range between \$1000 to \$2000 per award. Another member of the top ten, Notre Dame, does not appear to offer direct financial support for disabled students, but does prominently note that it provides assistive technology. Otherwise, information on these scholarships can prove quite difficult even for a dedicated researcher to find, let alone for the average student to stumble across.

Even outside of the most well-positioned institutions, these types of opportunities are not uncommon in the U.S. Careful searching online reveals that they can be found at a number of institutions, many of them larger universities, usually either in unspecified amounts or in the same \$1000–2000 award range. More problematic and perhaps more important, however, is that where they can be found seems to be quite unpredictable, and there is no immediately obvious centralized

mechanism for discovery of which institutions offer any scholarship options for disabled students and which do not. It is not clear how students would come to be aware of these awards' existence, if they were not specifically seeking out these types of funds at a particular institution. These are also, of course, all funds that are available only on an application basis and usually with substantial demands for demonstrating merit and documenting disability, and compared against the costs of university attendance, the amounts in which they are generally available are quite small for the amount of effort this process would cost time-strapped prospective students. In the case of both institutional scholarships and national ones, the fact that students must voluntarily seek them out raises even further barriers. It seems safe to assume that invisibly disabled and neurodivergent students, whose narratives have shown they are unlikely to identify as disabled or to feel comfortable seeking or accepting even small procedural allowances for their impairments, would be even less likely to seek out and apply for actual financial benefits, even if they are able to. This likelihood is particularly concerning, considering that these are the most common types of disabilities among college students, and they still impact students' necessary expenditures and earning opportunities like other disabilities do. The more students need to seek out outside employment to fund their education, as well, the more their time constraints will increase, and the greater their financial precarity, the greater the strain on their already impacted mental health.

Even so, the fact that some financial supports are available is a beginning, even if much more fundamental change may be needed to truly address the affordability of college for disabled students. Some authors have also suggested potential directions for improving the rates at which students actually connect to these funds in the meantime. Under the current circumstances, of primary importance is ensuring disability-specific financial aid information reaches disabled students, and every effort that can be made to make that information more accessible will be helpful. This work can begin with institutional web presence: not only ensuring that financial aid websites are fully accessible (Taylor, 2020), but also providing clear and easily findable disability-specific information there, to as much as possible eliminate the issues of 'hidden' scholarships described above (Perlow, 2021). Human support for aid awareness and

managing application processes is also of critical importance, just as the value of human support in academic advising and mentorship has been demonstrated in Chapter 7. The more guidance students can have in learning about aid, deciding to apply for it, and navigating those often arduous processes, the better.

#### Career Support

Similar principles apply to career support services for students with disabilities. This is another area in which students have expressed unmet need in their narratives, including for career support services and advice (Gallo et al., 2014), for increased targeted outreach by career services offices (Leopold et al., 2019), and other related services. Campus career support has failed to fully meet the needs of disabled and neurodivergent students for a number of identified reasons: career services staff are often unfamiliar with disabilities (Boeltzig-Brown, 2015), specialized services for these students' needs are often unavailable (Boeltzig-Brown, 2015; Andrewartha & Harvey, 2017), and those services that do exist are often underutilized (Boeltzig-Brown, 2015; Andrewartha & Harvey, 2017), probably in part because of these issues. Career services for students in these categories are not well represented in current literature either, such that there are few promising examples to draw from.

The U.S. National Technical Assistance Center on Transition (NTACT) produced a 2019 best practices document on employment transition, primarily aimed at secondary schools, but with potential for application at the postsecondary level as well. The areas of practice identified as promising for further expansion are as follows:

- Career exploration services, including training on job search skills;
- Work-based learning, e.g. mentorships, internships, shadowing, and volunteering;
- Counseling on opportunities for further education (meaning postsecondary education at the secondary level, and graduate education at the postsecondary), including planning, accommodations, supports, and similar concerns;

- Developing workplace-appropriate skills such as communication, collaboration, and metacognition skills; and
- Building self-advocacy skills. (NTACT, 2019)

All of these offer potential for developing specific services for neurodivergent and disabled students. Additionally, other authors have suggested practices specifically for students whom they identify as having learning disabilities. These include improving accessibility of career services offerings, encouraging student metacognition and self-efficacy skills, including self-assessment of employment-related strengths and challenges, and providing hands-on opportunities to become familiar with working environments—which align very closely to NTACT's recommendations above (Chen, 2021). Other recommendations include creating partnerships between disability services and career services (Verduce, 2019; Kwon et al., 2023), providing training for both staff and students as well as offering proactive specialized services (Verduce, 2019), and fostering disability identity, including by partnering strategically with organizations that provide disability-positive and strengths-focused working environments (Kwon et al., 2023).

At least one practical example has appeared in the literature as well: The Career Connect program for autistic students at Arizona State Polytechnic Campus and Case Western Reserve University (Meeks et al., 2015). This three-way partnership between career services, disability services, and counseling services was created to help connect students to the national Workforce Recruitment Program, which supports employment opportunities for disabled people. Relevant staff in the Career Connect program were trained on characteristics of autism and working with autistic people, including common strengths and weaknesses, and students who participated were provided with support groups, interview preparation, and career counseling. Meeks et al. (2015) report positive responses from participating students, and that 25% of their described cohort were subsequently accepted to internships for career preparation.

Similar programs to the Career Connect program may also be available at more institutions than the literature would suggest. For example, the Autism PATH Program at my home institution, Rowan University, also provides a number of career support services specifically to autistic students, but to my knowledge has not been published on to date. Deeper investigation into practice may reveal more promising examples of forays into this growing area. What is most important for now, however, may be recognizing the unique needs that disabled and neurodivergent students have for career services, and striving to better meet them.

## Improving Social Climate

Student narratives offer a number of suggestions for how to improve the social climate of higher education. Among the most common is increased training, education, and awareness-raising around disabilities for faculty and staff.<sup>3</sup> In particular, students note the need for faculty and staff to be more aware of the diversity of needs and presentations that may occur in students with accessibility and support needs, even between multiple students with the same neurodivergence or disability (Erten, 2011). Conley et al. (2019) also specifically notes that when supporting students coping with trauma and resulting psychiatric symptoms, there is a particular need for training and awareness around other marginalized identities these students may be impacted by, as experiences of oppression and discrimination may also be contributors to trauma. Autistic students, in particular, note the need for training for residence life staff on helping to manage their unique needs in living environments (Grabsch et al., 2021). Furthermore, some faculty also indicate that they are aware of gaps in their knowledge in this area and would like additional training (Zeedyk, 2019). Other suggestions regarding institutional employees include increased neurodiversity and diversity of ability among faculty and staff (Conley et al., 2019) and training in UDL principles and practices (Giroux et al., 2016).

Awareness-raising and training are also common recommendations students make for their peers, for that matter. In a number of studies, students either directly suggest that college students should be more broadly introduced to these subjects (Erten, 2011; Sarrett, 2017; Accardo et al., 2019b), or indicate that their peers' lack of knowledge

<sup>3</sup> Erten, 2011; Hubbard, 2011; Flowers, 2012; Randolph, 2012; Mullins & Preyde, 2013; Rutherford, 2013; Stampoltzis, 2015; Brandt & McIntyre, 2016; White et al., 2016; Pionke, 2017; Sarrett, 2017; Conley et al., 2019; Zeedyk, 2019; Anderson et al., 2020; Miller et al., 2020; Grabsch et al., 2021; Thompson, 2021; Turosak & Siwierka, 2021.

and misapprehensions are sources of difficulty (Gelbar et al., 2015; Thompson, 2021). Regarding faculty, staff, and peers alike, a number of students' narratives also recognize the prevailing ableism of the overall social environment of higher education, and call for consideration and implementation of systemic changes that would improve this atmosphere.<sup>4</sup> Some students with psychiatric disabilities express the desire for a more supportive higher education environment for these conditions in general, which would significantly lessen the severe impact that social stigma has on these students in particular (Turosak & Siwierka, 2021).

In academic libraries and similar campus units, Pionke's (2017) interview study of university library accessibility with faculty, staff, and students with disabilities yields several other valuable insights into how the social climate could be improved. Echoing students' recommendations about other higher education faculty and staff, interviewees in the study identify a need for more training for library staff in awareness of and sensitivity to the needs of disabled library users, especially those with invisible disabilities. Pionke also reaches two conclusions from common themes in interviewees' experiences: the need to empower neurodivergent and disabled users, and the need for empathy on the part of library staff. The issue of empowerment centers around eliminating common barriers of feeling intimidated or uncomfortable with the prospect of asking for support in the library. To this end, Pionke suggests that a combination of observation, collaborative discussion, and user research may serve as a way to identify solutions. The issue of empathy, meanwhile, centers on the need to examine and improve treatment of users with diverse needs within the library, which Pionke notes should occur not only on a personal but also a systemic level: 'Cultivating empathy within the library involves understanding not only our own reactions to the functionally diverse but also understanding how the library as an institution reacts and then taking steps to address both the personal and organizational deficits that are identified' (p. 55). Through staff training, conversations with users, and other methods, strategic work is needed across the academic library to understand what disabled and neurodivergent users need

<sup>4</sup> Mullins & Preyde, 2013; Gallo et al., 2014; Hughes et al., 2016; Turosak & Siwierka, 2021.

and how library staff can work with them to meet those needs, and to seek out and eliminate the ways that library staff, systems, and policies may frustrate and dehumanize users with these identities. What library workers learn and how they improve their skills in the process may also be shared outward through cross-campus collaborations, and have a positive impact on the culture of the university at large.

When it comes to matters of socializing, rather than social attitudes, there are also issues that institutions can help to address. A common theme across autistic students' narratives is that the opportunities for socializing on campus are not ones they find desirable. Multiple students describe the available social activities as uninteresting and unappealing, for personal as well as sensory reasons, with some negatively characterizing typical college socializing as a 'party scene.'5 These students do express a desire for opportunities to socialize, but indicate that their preferred opportunities would center around forming social connections with other like-minded students. This does not necessarily mean other autistic or neurodiverse students-although this is sometimes desirable-but simply others who share their interests, are serious about academic and intellectual pursuits, or both.<sup>6</sup> Autistic students frequently express a desire for the institution to facilitate social connections, by offering interest groups, support groups, and other similar student organizations.7 A few have also expressed desire for specialized versions of these facilitated connections: for example, helping autistic women connect with one another, or helping autistic students connect with neurotypical peers (Cullen, 2013). One way to facilitate social connections that seems to be helpful for autistic students is holding games and activities with explicit rules and structure, which autistic students may find more welcoming to participate in (Knott & Taylor, 2014). Conducting library research is also an area where autistic students tend to be able to excel and assist their peers, encouraging positive social experiences (Anderson, 2018; Everhart & Escobar, 2018). In academic settings as well, autistic students indicate that they have

<sup>5</sup> Tarallo, 2012; Cullen, 2013; Vincent et al., 2017; Gurbuz et al., 2019.

<sup>6</sup> Cullen, 2013; Drake, 2014; Bolourian et al., 2018; Colclough, 2018; Gurbuz et al., 2019; Anderson et al., 2020.

<sup>7</sup> Toor et al., 2016; White et al., 2016; Anderson et al., 2017; Colclough, 2018; Accardo et al., 2019b; Grabsch et al., 2021.

more positive experiences when deliberately included socially, even in cases where there are major barriers to social interaction for the student, such as for autistic students who do not communicate verbally (Ashby & Causton-Theoharis, 2012). Curricular tactics can help to improve students' social experiences beyond the classroom, along with other campus resources like formal support groups.

# Social Support Networks

A few promising practices have emerged by which institutions can facilitate social support networks for students, especially those who may struggle to find these organically. One interesting approach in this area is autism training for resident assistants (RAs), to help facilitate more welcoming and inclusive residential environments for autistic students (Bolourian et al., 2021). Given the challenges with living environments autistic students report, as discussed in Chapter 5, these types of initiatives could be particularly beneficial.

Support groups, however, are a much more commonly reported way that institutions try to build support networks, particularly for autistic students-although these are not without issues and challenges. Student buy-in for these groups varies significantly, and groups appear to be of less interest if they are designed with a deficit-based focus on building social skills, at too basic a level for the students participating, or not actually meeting the needs students had in mind: for example, providing a male leader for a support group explicitly for autistic women (Barnhill, 2016; Brownlow et al., 2023). Even when these pitfalls are avoided, though, group attendance can be a challenge (Barnhill, 2016; Brownlow et al., 2023). Smaller-sized groups seem to be most valuable, and those with mixed composition in terms of student level, so that they take on a mentoring aspect (Barnhill, 2016). Online support groups may also serve students better than in-person in some cases, especially if they are focused more on basic skills (Brownlow et al., 2023). Online support groups have also proven beneficial for dyslexic students, serving to protect students' privacy and increase the accessibility and adaptability of the group for students' needs (Grünke et al., 2023). Recommendations for developing this type of group include providing facilitators, maintaining closed groups for privacy, keeping group size small, establishing behavioral norms and ground rules, not limiting

students' length of participation, and making connections with outside organizations that can provide additional support (Grünke et al., 2023).

Particularly in recent years, however, another option has emerged for institutional support for student network-building: disability cultural centers (DCCs). These are locations on campus for disabled students that parallel cultural centers for other marginalized identity groups, and similarly create opportunities for socializing as well as holding events and programs, among other activities. This is still an emerging practice in higher education for the most part, with few centers established to date, and most of these relatively recently (Chiang, 2020). DCCs may be the most promising practice described in this area, however, not only for developing students' social supports, but also addressing many of the other issues identified in the foregoing narratives. For example, as is frequently noted, the parity of DCCs with other identity spaces helps to normalize the idea of disability as under the umbrella of diversity, equity, and inclusion work on campus, as well as bringing together disabled communities.8 Other work that DCCs help to facilitate includes advocating disability rights and addressing ableism on campus,<sup>9</sup> including working against internalized and lateral ableism within disabled communities (Kulshan, 2023), organizing advocacy programming (Chiang, 2020; Thomson, 2022; Kulshan, 2023), and facilitating connections between students and accommodations, especially when the DCC works in partnership with more administrative disability services units (Kulshan, 2023). DCCs also have strong potential to meet the need students have identified for disability- and neurodiversity-oriented social spaces on campus, as discussed in Chapter 5. Positive disability identity, which has also been established as associated with student success, has been identified as an impact of DCC implementation (Thomson, 2022), and some students view their role in the creation of a DCC as an opportunity to leave a legacy for other disabled students, making it possible not only for themselves to embrace pride in a disabled identity but to help others do so as well (Stewart, 2023). Other students simply find DCCs to offer a refuge from campus ableism, which is also a valuable defense for their mental health and well-being.<sup>10</sup>

<sup>8</sup> Chiang, 2020; Thomson, 2022; Saia, 2022; Fuller, 2023; Kulshan, 2023; Stewart, 2023.

<sup>9</sup> Chiang, 2020; Thomson, 2022; Saia, 2022; Stewart, 2023.

<sup>10</sup> Thomson, 2022; Saia, 2022; Kulshan, 2023; Stewart, 2023.

In most cases, DCCs have been established at the request of student activists, with varying amounts of effort required to secure administrative approval. A number of barriers may present themselves depending on climate, most notably unresponsive administrations, pathologizing and accommodations-focused attitudes toward disability on campus (Stewart, 2023), and a lack of recognition for disability as a culture, or of the need for a safe space (Stewart, 2023; Kulshan, 2023). Successful strategies for overcoming resistance have included campus disability education and awareness-raising, gathering evidence of support and need, demonstrations and protests, finding allies in the community including disabled or allied leaders in faculty and administration, seeking solidarity with other marginalized groups on campus, and reaching out to disability advisory bodies and disability studies programs (Stewart, 2023). The end results tend to vary widely in terms of their structural and physical location on campus, but are able to offer similar benefits to students regardless of format (Kulshan, 2023). Even once a DCC is established, however, its facilities are sometimes downplayed or pushed aside in terms of status on campus, especially compared to other cultural centers, with poor locations and facilities sometimes working against internal care and attention to accessibility (Saia, 2022; Kulshan, 2023). Even established DCCs may find they are often left out of campus considerations for DEI and cultural celebration (Kulshan, 2023). Clearly, DCCs still face a struggle to be afforded true parity with other cultural organizations on campus-but the promise they hold for students, not only for social but many other forms of support, solidarity, and advocacy, is worth the effort. The more institutions themselves can embrace DCCs and remove these barriers, the more successful and beneficial they can become.

#### Mental and Physical Health Care Access

#### Mental Health Care

Considering that mental health challenges are common for students across all categories, not only those with specifically psychiatric disabilities, it should come as no surprise that counseling services are often mentioned as a valued and desired support. Students across many studies recognize the value of effective counseling to their success and well-being.<sup>11</sup> Their experiences of using on-campus counseling services, however, tend to be far more mixed, with many students ultimately declining to access counseling through the institution because it proves insufficient to their needs.<sup>12</sup> For students with psychiatric disabilities, for example, limits on contact time in campus counseling can prohibit their developing the therapeutic relationship that they need for effective treatment (Demery et al., 2012; Cohen et al., 2022). Other studentidentified barriers to care include mismatches of hours and availability to their needs, the physical location of counseling on campus with regard to both its visibility and accessibility, and the demotivating nature of transition points such as moving from a pre-survey into counseling, being referred out of counseling, and similar (Cohen et al., 2022). Autistic students have been specifically identified as reluctant to use counseling services (Knott & Taylor, 2014), and have found common therapeutic techniques like cognitive-behavioral therapy to be unhelpful (Anderson et al., 2020). Furthermore, students who are preparing for mental health professions may be especially reluctant to use counseling services, as they are at risk of encountering peers from their programs in volunteer positions, thus compromising their confidentiality (Woof, 2021). In general, disabled students have been found to be more likely to selfterminate or be referred out of counseling than nondisabled students (Varkula et al., 2017), and while the study in question did not examine the reasons behind this pattern, the elements of students' narratives above may suggest some possible answers. As it stands, a number of students report finding mental health support that meets their needs either outside the university or not at all (Markoulakis & Kirsh, 2013).

This is not to say, however, that robust on-campus counseling is not at least theoretically desirable, and many student narratives explicitly state that it is.<sup>13</sup> For campus services to meet this need, however, they would require significant increases in funding and support, at the institutional

<sup>11</sup> Heiney, 2011; Flowers, 2012; Melara, 2012; Mullins & Preyde, 2013; Ennals et al., 2015; Toor et al., 2016; Anderson et al., 2018; Davis, 2019; Hoffman et al., 2019; Cox et al., 2021.

<sup>12</sup> Hubbard, 2011; Demery et al., 2012; Markoulakis & Kirsh, 2013; Turosak & Siwierka, 2021; Woof, 2021.

<sup>13</sup> Hubbard, 2011; Demery et al., 2012; Stampoltzis, 2015; Toor et al., 2016; Goodman, 2017; Accardo et al., 2019a & 2019b; Miller et al., 2020.

and governmental levels (Goodman, 2017). Nor are disabled students the only ones to identify insufficiencies in the current state of on-campus mental health care for their needs. A 2017 report focused on campus care for students with psychiatric disabilities identified a number of concerns, many of which echo those in student narratives: insufficient hours, lack of after-hours access, service fees, waitlists and treatment delays, session limits, referral process challenges, insufficient numbers of licensed staff, lack of diversity of staff, lack of availability of psychiatric services, and accessibility issues in treatment (National Council on Disability, 2017). Both students and campus clinicians have also identified a need for more satellite programs and services around face-to-face counseling, as well as better integration and promotion (Cohen et al., 2022). Clinicians have identified funding and staffing insufficiencies as critical barriers to their work, as well as lack of awareness and stigma or self-stigma on the part of students (Parker, 2023). A recent RAND research organization report similarly called for considerably more funding and structure for mental health resources for community colleges in particular (Sontag-Padilla et al., 2023), and clinicians in Parker (2023) go a step further and also identify increased financial support for students' basic needs as a critical intervention to improve mental health. Clearly, there may be no substitute for an institutional investment in students' mental health that is at least partly financial.

At the same time, the National Council on Disability report also identifies a large number of promising practices in campus mental health support. These include but are not limited to: stigma reduction and awareness-raising of psychiatric disabilities and counseling services, universal design strategies, collaboration with students and student organizations, suicide prevention and crisis management, telecounseling, substance abuse recovery, and collaborations with community mental health providers (National Council on Disability, 2017). While this list encompasses a very broad variety of practices, many of these can be seen in practice in the recent literature on campus mental health services.

For example, institutions have addressed issues of campus climate and awareness in a number of ways. Clinicians in Parker (2023) also identified stigma reduction around mental health as a critical need in delivery of campus mental health services, both in reducing barriers to care and increasing resources for providing care. They sought to address this need not only by simple strategies like making mental health crisis information prominently available online, but by working to create a more holistic 'culture of care' throughout the university. A promising tactic for doing so, across multiple studies, is enlisting the support of faculty and staff, by providing training and resources to help them provide basic mental health interventions for students (Blokland & Kirkcaldy, 2022; Pierce, 2022; Parker, 2023). Pierce (2022) also mentions the value of faculty including mental health information in course syllabi, and notes that this serves as a form of outreach that may be effective where others are not.

Various promising practices have also been implemented in order to address staffing concerns for campus counseling centers and other mental health services. Some institutions have begun outsourcing for additional access to counselors and help lines (Pierce, 2022), or partnering with local or national organizations for additional staffing and expertise (Blokland & Kirkcaldy, 2022; Pierce, 2022). Coll et al. (2024) also report on community college partnerships with universities, to provide staffing by students in clinical mental health programs at low or no cost. Unique staffing models have also been put in place at other institutions to maximize limited resources, such as virtual workshops on mental health topics led by 'peer helpers' during the COVID-19 pandemic (McConney, 2023). Still other institutions have begun to experiment with deploying embedded therapists, located either exclusively or partially in other locations outside the counseling center, often to serve specific communities or cohorts, increase access to counseling, or both (Schreier et al., 2023). A similar recommendation is to embed culturally matched counselors within campus cultural centers, to better meet the needs of marginalized communities (Quimby & Agonafer, 2023).

Another increasingly common approach to staffing concerns is to employ what Blokland & Kirkcaldy (2022) refer to as a 'stepped-care model': a model in which counseling patients are moved to escalating levels of intensity of service based on their individual need, from screening to low-intensity care to higher-intensity care. Lower-intensity care may be able to be handled by informal interventions, like online services and apps, or by less credentialed and less experienced staff, while higher-contact care requiring more expertise is reserved for patients with the greatest need. This type of triaged, hybridized care has been found to have the potential to eliminate waitlists and reduce counselor burnout (Parker, 2023). The workshops offered by peer helpers in McConney (2023) serve as one example of the possibilities for lower-intensity care practices, and a health and wellness coaching program described in Bleck et al. (2023) serves as another.

Online services and applications are another fast-growing area of development in providing lower-intensity types of services. Positive impacts have been reported for these types of asynchronous interventions for students at elevated suicide risk or with depression or anxiety, and can be deployed while students are waiting to see a counselor (Haeger et al., 2022; King et al., 2022; Rith-Najarian et al., 2024). These types of digital implementations are still at an emerging stage, however, and while both students and campus clinicians have expressed interest in mental health apps, as of yet these have generally not been used or promoted except as a way of triaging face-to-face care-which means they still do not reach students who would not be willing to enter counseling in the first place (Cohen et al., 2022). One innovative example of work to remove this barrier, however, involved creating a service-learning project for clinical psychology students to evaluate widely available mental health apps, and then using their recommendations as the foundation of a major promotional push to the rest of campus about the apps (Stanger & Lucas, 2024). This project was promising not only in terms of increasing awareness and use of low-impact mental health interventions, but in its incorporation of campus mental health support into the curriculum and pedagogy, providing a sense of student ownership and peer support.

New approaches to service delivery also promise to expand access to campus mental health care for students, especially those developed within the past few years. One of these is integrations between campus mental health care providers and medical care providers. Often coinciding with the new construction of single integrated physical facilities, these collaborations have been found to be able to provide holistic care to students, with overwhelmingly positive responses, including significant increases in numbers of appointments, and anecdotal testimony from students that the integrated center itself played a vital role in preventing their attrition from college (Reynolds, 2022). These impressive results are particularly important given evidence that this type of single point of holistic care is particularly desirable and necessary for first-generation students from marginalized communities (Coronado, 2022). There are challenges associated with integration, including merging often different work cultures and teams, but more significantly the protection of students' privacy when sharing medical records between providers (Davenport, 2017; Reynolds, 2022). Still, integrated services appear to hold the promise of substantial value for students in a variety of different ways. For example, one institution found success with providing a 'BodyMind Approach' support group program as a referral for students with medically unexplained symptoms, which proved a more accepted way to introduce students into mental health care who would otherwise have been resistant (Payne, 2022). Blokland & Kirkcaldy (2022) also note the need for integration in cases where students' challenges with access to pharmaceutical and other medical care come up in the course of counseling. If the challenges around privacy and otherwise can be addressed, this may prove to be an extremely worthwhile area of practice for more institutions to pursue.

Another relatively new mental health service approach that has boomed as a result of the COVID-19 pandemic is telecounseling. This dramatic increase has included higher education mental health services, and is evident internationally as well, for example in South Africa (Blokland & Kirkcaldy, 2022). University mental health professionals have identified telecounseling as a critical innovation to address changing and increasing student needs (Parker, 2023), and students have found it a satisfactory alternative to face-to-face counseling and expressed willingness to use it, especially if cost factors are eliminated (Gonzalez et al., 2023; Ahuvia et al., 2024). This is a notable reversal from pre-pandemic study results that indicated much more hesitancy around telecounseling as a theoretical practice (Gatdula et al., 2024). Clinicians have also found telecounseling to largely be a satisfactory alternative to face-to-face counseling, noting its convenience for students and higher levels of observed treatment adherence, although there are some technological drawbacks as well (Hersch et al., 2024).

A few other relevant examples of new mental health service approaches have also been noted. One of these is programs available specifically for students with serious mental illnesses, which has become an area of greater need due to the increased access these students have begun to gain to higher education; some institutions have begun to work toward developing programs with more intensive therapeutic strategies and schedules to make higher education more fully accessible for students with the greatest needs for psychological and psychiatric care (Mason, 2023). Another initiative brought together campus clinicians and students to discuss barriers and needs for care, and from there to co-design workshops for the campus community; this was highly successful, and in the long term resulted in the recommendation to form a student advisory board for counseling services (Cohen et al., 2022). Working collaboratively with students toward changes in mental health care may be a valuable first step for any institution, regardless of what other strategies may subsequently be employed.

#### Medical Care

Physical medical care is also a significant need for students in multiple categories, as well as mental health care. One particularly needed service in this area is pharmaceutical services and medication management. Many student narratives confirm that appropriate medications can be highly beneficial for many different types of impairments, but also that identifying an effective medication and then maintaining a regular dosage can be arduous processes.<sup>14</sup> For example, side effects of an otherwise beneficial medication can put additional strain on students' physical health.<sup>15</sup> Taking medication, particularly medications for psychiatric impairments and ADHD, is also frequently stigmatized in itself, compounding other stigma that students experience.<sup>16</sup> Stigma and social pressures against medications may be particularly acute for students from Asian American and immigrant families, to the point that they may be prevented from accessing medications until the age of majority (Young, 2012). There is also significant negative social pressure for students preparing for mental health professions, due to professional biases against certain medications in their programs and

<sup>14</sup> Hubbard, 2011; Melara, 2012; Randolph, 2012; Lefler et al., 2016; Anderson et al., 2017; Bolourian et al., 2018; Giroux et al., 2020.

<sup>15</sup> Zafran et al., 2011; Melara, 2012; Markoulakis & Kirsh, 2013; Hong, 2015; Lefler et al., 2016; Bolourian et al., 2018.

<sup>16</sup> Randolph, 2012; Young, 2012; Lefler et al., 2016; Bolourian et al., 2018; Woof, 2021.

among their peers (Woof, 2021). For students taking medication for ADHD, there is also the complicating factor that these medications are seen as desirable for off-label use by young adults in college, and students whose peers learn they take them may face resentment for a perceived unfair academic advantage (Young, 2012), or social pressure to illicitly provide medication to friends and classmates (Lefler et al., 2016). Readily available access to medication management services, with a high level of emphasis on discretion and privacy, would be beneficial to many students in handling another stressful drain on their time and energy.

One emerging practice that could benefit these students and others is the provision of on-campus pharmacies. These have begun to be available at some institutions in the U.S., mostly at larger institutions outside of the northeast region (Davis et al., 2020). They tend to be on the smaller side, however, with relatively few staff and short hours, and are often subject to other service limitations like uneven Medicaid and Medicare coverage, limited discount programs and cards, fewer medications available, and lack of common services for convenience and adherence like automatic refills (Davis et al., 2020). As a result of these factors and other design elements, campus pharmacy locations are often subject to financial precarity, and have been found to underutilize opportunities to partner with colleges of pharmacy on campus, or to supply preventive care services to the student population (Davis et al., 2020; Mathew et al., 2021). Greater attention to increasing these types of on-campus facilities, and developing much more robust services available there, could be tremendously beneficial not only to invisibly disabled and neurodivergent students, but to the entire campus population.

More generally, other aspects of medical care are also important for students across categories, but particularly for chronically ill students. Physical symptoms like pain or mobility difficulties, whether they arise from conditions directly or from aspects of treatment like medication side effects, can be significant and disruptive stressors for students.<sup>17</sup> Neither is this only true of chronically ill students. In fact, some autistic former students cite poor physical health as a major factor in their college non-completion (Anderson et al., 2020). More promisingly, however, more

<sup>17</sup> Bush et al., 2011; Markoulakis & Kirsh, 2013; Hong, 2015; Childers & Hux, 2016.

positive experiences with campus medical care seem to be reported in the literature than with campus mental health care (Hoffman et al., 2019; Turosak & Siwierka, 2021). Students also frequently mention medical care and access to healthcare practitioners as a valuable support, but most of those who mentioned this were actually accessing care outside of campus, rather than through campus health services (Kreider et al., 2015; Ravert et al., 2017; Giroux et al., 2020). There also appears to be less evidence of practical innovations in the current literature in this area than in campus mental health, although this may simply indicate that campus medical facilities are not experiencing the same crisis of need that mental health services are. A few recent innovations are in evidence that may hold promise, as well, such as using de-identified student datasets for proactive prevention strategies for return-to-campus planning during the COVID-19 pandemic (Tanabe et al., 2023), and the increasing availability of campus telemedicine as well as telecounseling, although this has also mostly been limited to larger and more resourced institutions (Hollowell et al., 2024). Both of these approaches have potential value for disabled and other vulnerable members of campus communities, and are worth pursuing.

In any case, as with mental health services, campus medical services must be adequately resourced to provide robust and comprehensive care, in order to properly support this population. If at all possible, as well, it would be extremely valuable for institutions to consider offering on-campus access to sleep medicine as one of these services, given the significant issues with sleep disruption noted across student narratives. Having these types of supports available within the institution could significantly contribute to students' success and well-being, if properly implemented.

### Skill-Building and Information Support

While it is of most importance to materially adapt the college environment to meet students' needs, there are some ways that students can also be supported by helping to build their own skills and knowledge. As discussed in previous chapters, there are valuable skills for students to learn for higher education and for life beyond it, which the institution could support by providing explicit training. Metacognition, developing and using memory aids, time management and organization, maximizing limited executive function, self-advocacy, and stress management are only the most prominent examples. Efforts at the institutional level to reach out to students with instruction and support in these skills could have significant benefits.

Some students also note, however, that obvious self-service supports at the point of need, such as online tools that are easy to find and access, are also extremely important to maintain (Hubbard, 2011). Indeed, while there are many cases where students may need training or staff support with navigating necessary information, there are also equally important needs for information that students can access independently and privately, such as on sensitive topics like stigmatized disabilities, gender identity, and sexuality (Anderson, 2018). Academic libraries, in particular, may be able to help in this area, by improving the ways in which they already support both types of information need. Library staff are uniquely well-positioned to help students find information about disabilities and college skills, and could advertise this service specifically, as well as ensure libraries have a wealth of electronic resources on topics that students may want to explore privately.

In terms of active support programs from institutions and beyond, however, some promising efforts are described in the literature. This is true even excluding practice at the secondary school level, where a large number of university readiness and transition efforts appear to be concentrated. As seen in Chapter 7, mentoring and coaching programs have been reported to have a significant positive impact on many of the skill and information areas that students' narratives have identified as most critical. There are also reports of other training programs and resources more specifically focused on developing self-advocacy and college navigation skills, however, that deserve attention. The programs and resources described include those aimed at students with any disability (although invisibly disabled and neurodivergent students tend to be most represented in the actual populations served),<sup>18</sup> those aimed at autistic students,<sup>19</sup> and to a lesser degree, those aimed at

<sup>18</sup> White et al., 2014; Nazaire, 2018; Ford et al., 2019; Button et al., 2019; Rothwell & Shields, 2021; Rolander et al., 2021; Holzberg & Ferraro, 2021.

<sup>19</sup> Retherford & Schreiber, 2015; Organization for Autism Research, 2018; Nachman, 2020; Bellon-Harn & Manachaiah, 2021; Yeager, 2022; Nachman, 2022; McDonald

students with ADHD and unspecified learning disabilities (Farmer et al., 2015; Russell & Pearl, 2020).

The offerings described are diverse in terms of format, although there are a few areas of overlap. The most common type of delivery method, unsurprisingly in light of the results reported in Chapter 7, is one-onone consulting or coaching programs, but aimed at these specific skill areas rather than establishing a more general mentoring relationship,<sup>20</sup> and in one case, specifically with disability services staff (Rothwell & Shields, 2021). Two studies also described intensive campus experiences in the form of multi-day residential training, for students at the point of transition from high school to college (Retherford & Schreiber, 2015; Ford et al., 2019). Most other programs and resources were also targeted toward transitioning students, as well, although with less immersive and more varied formats: a virtual bridge program (Rolander et al., 2021), a support program that began in a face-to-face format and then moved online (Brownlow et al., 2023), a free-to-download short book for self-study (Organization for Autism Research, 2018), and a credit course in the first year of college (Nachman, 2020). Other programs and resources were mostly virtual to some degree, including a set of online modules and in-person workshop (White et al., 2014), a video training resource (Russell & Pearl, 2020), and an online learning and support application (Bellon-Harn & Manachaiah, 2021).

The specific content covered by these offerings similarly varies, although it also falls into rough categories. These include:

• Campus life knowledge. Aspects of navigating college, including academic studies, living arrangements, social skills including around residential life, wellness, financial management, technology support, safety, majors and careers, and more.<sup>21</sup> Additional related topics include the 'hidden curriculum' of college (Retherford & Schreiber, 2015; Organization for Autism Research, 2018), and careers and transitions to life after college (Organization for Autism

et al., 2023; Brownlow et al., 2023.

<sup>20</sup> Farmer et al., 2015; Button et al., 2019; Rothwell & Shields, 2021; Holzberg & Ferraro, 2021.

<sup>21</sup> Retherford & Schreiber, 2015; Organization for Autism Research, 2018; Ford et al., 2019; Button et al., 2019; Rothwell & Shields, 2021; Bellon-Harn & Manachaiah, 2021; Brownlow et al., 2023.

Research, 2018; Ford et al., 2019; Brownlow et al., 2023). The self-study book investigated also notably covered dating and relationships, including consent and sexual assault, and financial aid navigation (Organization for Autism Research, 2018).

- Accommodations. Understanding available accommodations in college, especially in the context of how the system differs from secondary settings.<sup>22</sup> Other subtopics included disability rights in college (White et al., 2014; Organization for Autism Research, 2018; Russell & Pearl, 2020), hands-on skills in accessing accommodations (White et al., 2014; Russell & Pearl; Rothwell & Shields, 2021), and the definition of 'reasonable' accommodations (White et al., 2014).
- **Self-advocacy.** Training in practical skills and techniques for self-advocacy and negotiation.<sup>23</sup> Notably in one case, also the rationale for why self-advocacy is important, and why students should feel justified in employing it (Nachman, 2022).
- Metacognition. A number of areas of focus related to metacognition, including self-identifying personal strengths (White et al., 2014; Farmer et al., 2015; Rolander et al., 2021), self-reflection (Retherford & Schreiber, 2015), positive self-acceptance (Organization for Autism Research, 2018), and theory of mind (Retherford & Schreiber, 2015).
- Organization and self-management. Relevant topics include self-developing structures and routines (Organization for Autism Research, 2018), executive functioning, and individualized goal-setting (Retherford & Schreiber, 2015). Several programs also included a mentoring component that focused on these types of skills, either with faculty and 'realworld partners' as mentors (Retherford & Schreiber, 2015), or undergraduate student peers (Ford et al., 2019; Brownlow et al., 2023).

<sup>22</sup> White et al., 2014; Organization for Autism Research, 2018; Rolander et al., 2021; Brownlow et al., 2023.

<sup>23</sup> White et al., 2014; Button et al., 2019; Russell & Pearl, 2020; Rolander et al., 2021; Holzberg & Ferraro, 2021; Nachman, 2022; Brownlow et al., 2023.

Reported outcomes from these programs and resources were generally positive, although cautiously so. All types of approaches received generally positive affective responses from students,<sup>24</sup> even when actual student engagement in a program was relatively low (Brownlow et al., 2023). Both intensive residential experiences also saw students and their parents reporting positive impacts on students' life and social skills, including confidence, college and career readiness, and self-advocacy knowledge (Retherford & Schreiber, 2015; Ford et al., 2019). A number of interventions also found increased self-reported confidence in self-advocacy skills (Russell & Pearl, 2020; Holzberg & Ferraro, 2021; Nachman, 2022) and academic skills (Bellon-Harn & Manachaiah, 2021). As with general mentoring programs, however, otherwise results were more mixed, with cases of demonstrated improvement in skills that were lower than anticipated (White et al., 2014), low empirical impacts in spite of strong student engagement and self-evaluation of improvement (Farmer et al., 2015; Button et al., 2019), marked increases in some targeted skills but much less in others (Rothwell & Shields, 2021), and high program completion rates but moderate success rates in employment and education goals (Rolander et al., 2021). A different and notable positive outcome reported in Brownlow et al. (2023), however, was that student participant co-design when revising the program led to a positive transition in format (Brownlow et al., 2023).

More concerning in this area of the literature, however, is that there has been a general tendency toward deficit mindset and a lack of engagement with critical disability theory, as noted by Nachman (2020). This is a complex issue that applies to several of the promising practices that have been described in these two chapters. On the one hand, the core purpose of higher education is of course for all students to build their skills and knowledge, and it does not necessarily reflect a problematic deficit mindset to develop programs to accomplish this goal with students who have a particular need. On the other hand, if it is seen as a complete solution to implement programs to improve disabled and neurodivergent students' skills at overcoming the barriers that higher education imposes on them, without engaging with the need to remove those barriers as well, then these approaches are in fact

<sup>24</sup> Retherford & Schreiber, 2015; Farmer et al., 2015; Russell & Pearl, 2020; Rolander et al., 2021; Bellon-Harn & Manachaiah, 2021; Nachman, 2022; Brownlow et al., 2023.

incomplete, and situated in the medical model that views students' needs as their own deficits to be remedied. This conclusion is only reinforced by Woolf and de Bie's (2023) striking interview study, led by disabled students, that troubles the entire area of focus on self-advocacy skills. The students' critique of this concept points out not only that this model locates the responsibility for systemic barriers with students rather than with the system, but also that there are hidden assumptions of the 'right way' to self-advocate. Students are expected to acquire the 'stamp of approval' of formal accommodations, demonstrate physical or visual signs of having a disability, behave as much as though they were nondisabled as possible, and make the people to whom they are advocating as comfortable as possible: whether by embodying white gender-conforming norms of respectability in personal appearance, self-blaming instead of correctly identifying courses and requirements as inaccessible, not displaying emotion, managing others' emotions, and disclosing as much (sometimes private) information about their health and needs as possible (Woolf & de Bie, 2023). Students in this study also identified more promising practices for themselves, in terms of resisting these expectations. These included prioritizing their own time and energy, minimizing the amount that they disclose about their conditions even if that means they are not as 'accommodated' as they could be, finding disabled community for support and solidarity, and refocusing their conversations on how institutions could improve accessibility and accountability, and change in order to make self-advocacy less necessary. This important work should prompt us as educators to reflect: how should we respond and set our priorities, if students' low rate of seeking formal accommodations is not a problem for us to solve, but instead what students have identified as their own form of best practice? While efforts to develop students' skills are not wasted, how might we direct the greater share of our energy toward those that are more fundamental, more transformational, and more challenging?

#### Summary and Conclusions

As in Chapter 7, the practice examples described here include many aspects that are promising for meeting students' most expressed needs, and also many areas where further work is needed to reach the

full potential of these efforts. Local and national funding sources are available across much of the world for the financial need of disabled students, but more work is needed in facilitating students' connections to these funds, and ensuring that invisibly disabled and neurodivergent students have equitable access to them. Questions also remain about how much gatekeeping of financial supports (such as an application) is even necessary, and whether broader, lower-threshold access to funding is not the greater imperative than asking students to invest substantial efforts for small, uncertain gains. Career support programs for disabled students may be more common than they appear, but substantial data has yet to become available on how these function, where they are successful, and where they need to improve. Students have made numerous recommendations about how to improve the campus social climate for them, but some of the most promising, like disability cultural centers, face significant pushback and marginalization from campus leadership. The need for more comprehensive campus mental health and medical care has been recognized, and a number of innovative approaches have been implemented to try to address the gaps, but more resources for these services are still urgently needed. While many programs have been implemented to help students learn skills around navigating college systems, the barriers these systems present in the first place have received less attention, placing the onus on students to work around them rather than on institutions to become more inclusive and equitable.

This is not to undermine the value of the existing work toward improving disabled and neurodivergent students' experiences, because it is valuable. As also mentioned in Chapter 7, every positive change and effort to reach out to these students helps, and is demonstrably appreciated. There are simply directions along which it would be most beneficial for the work to continue, and they are generally not the easiest ones. For example, ultimately, interventions like mentoring and skill training unquestionably have positive impacts; they are empirically beneficial to varying degrees, and students appreciate and make use of them, and see benefit from them. It is also important, however, to exercise great care in framing the purpose of these interventions, and how they fit into the larger ecosystem of making change. Helping students learn to navigate college is very helpful in orientation to a new environment, but it does not mean that university processes should not be reviewed to make them as user-friendly as possible. Metacognitive and negotiation skills are valuable for students to learn to support them throughout their whole lives, but equipping students with these does not absolve institutions of also addressing the barriers and ableism that students could use these skills to fight. The entry of disabled students into higher education is not the problem; the problem is the multiple ways in which the higher education environment is set up to privilege only students with certain bodies and minds. Changing these is most imperative, and also most complex and difficult. It requires buy-in, imagination, and effort from all levels of the institution, including those with the most power in decision-making, which individual faculty and staff can seldom directly control. We can, however, work toward change at these levels by forming coalitions with students themselves-such as in the example of campus faculty and staff lending their voices to student advocacy for disability cultural centers. But this can only occur if faculty and staff recognize the importance of the work, understand that the institution rather than the students is in need of change, and are willing to view students as our priorities and partners, facing true inequities and with legitimate concerns, rather than as bad faith actors seeking to shirk work and obtain undeserved benefits.