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**JPED Author Guidelines**
Since joining the JPED team this year, we have used our editorials to interrogate and more deeply consider disability as a multifaceted and contested concept, as well as part of our daily and professional language. For researchers, these issues lead to several challenging decisions that can lead a study to reinforce societal and academic ableism, or can position that same study to challenge ableist norms while informing practice to improve postsecondary education. One goal of research should be to represent the diversity of disability and wide range of experiences disabled people have in postsecondary education. However, this aim can be in tension with efforts to understand trends and phenomena empirically, which often mean grouping people together in meaningful ways.

Intersectional approaches are one way to enrich disability research by recognizing and studying the diversity within and across groups, providing a more nuanced look at the trends and experiences of students. Intersectionality recognizes that multiple systems of oppression (e.g., racism, heterogenderism) interact and interlock with ableism to differentially impact disabled students in higher education. In some research, students’ multiple identities can be included in research designs to attempt to better understand students’ experiences with these intersectional systems of oppression. Notably, given the multivalent nature of disability, these intersecting identities—and related systems of oppression—can also include multiple disability identities.

For example, while some disabled people have the option to pass for non-disabled in some or all spaces, others have disabilities that are readily apparent in most or all contexts. The way that disabled people internalize or experience externalized stigma can therefore vary tremendously. Likewise, differentiating among forms of ableism—for instance, noting the mutually reinforcing logics but separate manifestations of a lack of physical accessibility, an inattention to mental health, and limited alternative access options for those with chronic health conditions that render them immunocompromised—invites scholars to be attentive to multiform tactics with which academia maintains its ableism. Distinguishing among these ableist strategies can help us to understand when and why some disabled people experience them while others do not.

In this issue, multiple articles either directly or indirectly address students whose disability would likely not be known or realized by others in many situations. These are referred to as “invisible” or “non-apparent” disabilities by the authors, or simply by a specific type of disability that is typically non-apparent (e.g., anxiety disorder). As group, these articles have us thinking about the ways that apparentness of disability, as an additional vector of identity and experience, must be considered. Given that apparentness of disability is related to individuals’ self-disclosure decisions, it is an important factor in postsecondary processes of gaining services and accommodations. Apparentness is also related to others’ perceptions of the “legitimacy” of one’s disability, and in turn their perceptions of the “fairness” of accommodations that may be received.

Several areas for empirical inquiry rise from such considerations. What does intersectional research that considers apparentness look like? What are key questions the field needs to explore regarding the spectrum of apparentness related to disability services? How can this knowledge help disability professionals to create conditions to serve each student in the most appropriate way, including a consideration of apparentness?

Articles in this issue move the needle on our knowledge about apparentness of disability, and do so in different ways, some directly and some indirectly. Together, they provide a point from which to think more critically and intentionally about apparentness as an aspect of disability in postsecondary education and may serve as a foothold to generate additional questions for future research.

In the first article, Will Lindstrom, Jennifer H. Lindstrom, Trisha T. Barefield, Mary Hall Slaughter, and Erin W. Benson examine the use of extended time accommodations for students with learning disabilities, ADHD, and/or psychological disabilities. As a common accommodation, the perception of fairness is central to this inquiry. Ultimately, the authors find wide variation within and across disability types, reminding us of the individualized and heterogeneous nature of disability among those with nonapparent disabilities.

Female college students with chronic illness are the focus of the second article, by Danielle Barber and James L. Williams. As they point out, women face more shame, stigma, and blame than men regarding chronic illness. The question of self and others’ perceptions of the fairness of accommodations is again important to the story. Additionally, they find that these students often feel misunderstood, have the legitimacy of their disability questioned, and feel pressure to take online rather than in person classes,
even as many students successfully use coping and management strategies to succeed in college.

Amy Hasman and Cynthia Matlock examine self-advocacy for students with anxiety disorders. Self-advocacy has an important role in the postsecondary experience of students with non-apparent disabilities, when it comes to disclosure, registration, and attainment of accommodations. The authors find that while the value of self-advocacy was recognized by most, it was challenging for many students. In turn, they experienced impacts on their health management, education participation, communication management, social participation, and sleep participation.

Caitlin A. Rothwell and Joseph J. Shields analyze data from a proactive advising model open to all disabled students at one institution. Students reported perceived improvement in their organizational and study skills after participation in the advising. Notably, the majority of the participants in the study had nonapparent disabilities (e.g., ADHD) and may especially benefit from such an intervention.

Allison Lombardi, Laura Buenner, Julia Loose and Olaf Hoos present research validating the German translation of a survey instrument that has been used in the US to explore faculty attitudes toward inclusive instruction. This is an important step in pushing the measurable aspects University Design tenets beyond the English-speaking parts of the world, in order to provide comparative research findings but also to better serve students around the globe. In the German context, they report that most disabled college students have “non-visible impairments,” showing the importance of their efforts for that subpopulation.

While emotional support animals (ESAs) may be used by a wide range of disabled students, those with some nonapparent disabilities (such as anxiety and chronic illness, examined in this issue) are among the most likely to use them. The ways these animals are approved and used on campus, is explored by Lauren E. Poindexter and James C. Marconi. Their practice brief outlines how one institution considered restrictions, documentation, and benefits of ESAs, in the hope that other practitioners can consider what is best for students on their campuses.

Finally, Karly Ball provides a review of the book Being Heumann: An Unrepentant Memoir of a Disability Rights Activist. This look at the life of Judy Heumann—a disability rights activist who has advocated for rights in K-12 education, postsecondary education, the workplace, and globally through her work in the US government—would be interesting and informative to any reader. This review, however, shows how disability service providers may glean particular importance from it for their work with disabled college students.
Examination of Extended Time Use Among Postsecondary Students with Non-Apparent Disabilities

Will Lindstrom¹
Jennifer H. Lindstrom¹
Trisha T. Barefield¹
Mary Hall Slaughter¹
Erin W. Benson¹

Abstract

The study investigated the amount of extended time (ET) used by postsecondary students with learning disabilities, attention-deficit/hyperactivity disorder (ADHD), and psychological disorders granted a 50% ET accommodation (i.e., time and one-half). Extended time used was evaluated by disability type, including comorbid presentations, and year in school. The sample was composed of 2,227 undergraduate course tests taken with ET. ADHD was the most common disability, and the majority of tests (75%) were taken by upperclassmen. The average amount of time used on tests taken with ET was well below the amount granted, and no pattern emerged to suggest a connection between disability type and amount of time used. Further, tests taken by individuals with multiple disabilities generally did not require greater amounts of ET than tests taken by individuals with single disabilities. Implications and recommendations regarding disability service access and ET as an accommodation are discussed.

Keywords: extended time, accommodation, postsecondary, learning disabilities, ADHD

Extended Time

Testing accommodations are “alterations to tests’ standard administration procedures that are made to overcome individuals’ functional impairments, in order to increase the validity of inferences that can be made from the resulting scores” (Kettler, 2012, p. 53). Extended time on tests is an accommodation commonly granted to students with disabling conditions that hinder the efficiency at which they access a test, compromising their ability to demonstrate...
knowledge or skills within the standard allotted time (Lovett & Lewandowski, 2015). Theoretically, ET should allow SWDs equal access to test content, resulting in improved test scores. As posited by the interaction hypothesis and maximum potential thesis, students without disabilities should not benefit from ET, already having sufficient test access under standard conditions (Sireci et al., 2005; Zuriff, 2000). Alternatively, the differential boost theory posits that students without disabilities might experience some benefit from ET, but the benefit would be significantly less than that experienced by SWDs (Fuchs & Fuchs, 2001). Interestingly, research has not consistently supported any of the noted theories. For example, some studies have found that college students with ADHD or LD provided ET are able to access more items than students without disabilities allotted only standard time, yet students without disabilities actually benefit more from ET than students with ADHD or LD when both are granted ET (Lewandowski, Cohen, & Lovett, 2013; Miller et al., 2015). In the context of the notable flaws of ET as an accommodation, surprisingly little attention has been paid to the amounts of ET that would minimize resulting unfairness.

Extended time is frequently provided in amounts of 50% (time and one-half; e.g., 90 min for a 60 min test) or 100% (double time; e.g., 120 min for a 60 min test) extra time. Historically, 50% has been the default duration when granting an ET accommodation, but this practice has been criticized for a lack of empirical support (see Sokal & Vermette, 2017). Other findings suggest that 25% ET is a more appropriate allotment, as it balances access and fairness. Cahalan-Laitusis et al. (2006) found that students with LD and/or ADHD taking the SAT with 50% ET tended to use less than 25% ET. Similarly, Lewandowski, Cohen, and Lovett’s (2013) findings suggested that college students with LD may require additional time on speeded tests, but that “25% extra time may suffice for the typical LD student, 50% extra would be more than what some students require, and 100% extra time would confer an unfair advantage for some students with LD” (pp. 333-334). Despite these findings, the use of 25% ET is quite rare (Weis et al., 2019).

**Predicting Extended Time Need and Appropriate Duration**

Little empirical evidence exists to inform ET need and duration recommendations. Research with college students with LD has indicated that some measures of academic fluency may have utility in predicting the likelihood of improvement when granted ET, but correlations between the measures and a dichotomous “need ET/does not need ET” variable have been modest, at best (e.g., -.38; Ofiesh et al., 2005). Findings for the predictive utility of cognitive processing speed scores were inconsistent in two previous studies (Ofiesh, 2000; Ofiesh et al., 2005). More recently, Lovett and Bizub (2019) found that none of six cognitive diagnostic performance tests significantly predicted access to items on a timed multiple-choice reading comprehension test. In general, authors of such studies have concluded that test scores represent only one of many variables to be considered when determining ET durations. The conclusion that test scores alone are insufficient is generally accepted due to the lack of empirical evidence demonstrating the association between diagnostic and real-world tests.

Despite the recognized importance of basing accommodations on functional limitations instead of diagnostic label (Gordon et al., 2002), it is not surprising that some professionals appear to base ET recommendations on the mere presence of a diagnostic given the paucity of effective predictors of a need for ET. For example, reviews of documentation submitted to disability services offices in support of accommodation requests indicate that it is common for ET to be recommended for students diagnosed with ADHD in the absence of evidence supporting need (Nelson et al., 2014; Weis et al., 2019).

**Importance of the Study**

In the current study, the amount of ET used by college students was investigated to determine if the ET granted provided them with sufficient time, too little time, or more time than they required to complete tests. The amount of ET used during tests warrants scrutiny due to the potential consequences associated with students being provided too little or too much time. Students with disabilities who are not granted a commensurate amount of time to access a test when compared to students without disabilities experience discrimination. On the other hand, evidence indicates that SWDs granted too much ET outperform students without ET (Lewandowski, Cohen, & Lovett, 2013), and that use of ET by SWDs results in scores that over-predict later academic performance (Cahalan et al., 2002; Thornton et al., 2002). Ultimately, ET is an accommodation that breaks a standard procedure, with potential to compromise the comparability of scores across test-takers when not allotted appropriately. When considered within the context of concerns from faculty that accommodations are compromising fairness (Pardy, 2016; Trachtenberg, 2016), findings that evaluators—acting in more of an advocacy role than an objective role—are recommending accommodations too liberally (Harrison et al., 2013), and a clear desire for ET by students regardless of disability
status (Lewandowski, Cohen, & Lovett, 2013), more precision is needed when determining who should have ET and how much time should be granted.

**Review of the Relevant Literature**

Much of the previous research on ET has been conducted using analogue designs (see Lovett & Lewandowski, 2015 for a review). A limitation to these studies, however, is that they were conducted in simulated test settings in the absence of any external motivation to perform well. Participants in research studies have been found to sometimes put forth sub-optimal effort, given the low stakes (An et al., 2017). The current study examined use of ET in an authentic setting in which test scores counted toward course grades, significantly augmenting the ecological validity of the findings. As a result, students’ effort and motivation were also authentic, allowing a clearer depiction of ET need versus want.

Three prior investigations have evaluated the use of ET by SWDs in a similar fashion. Holmes and Silvestri (2019) examined the amount of ET used by students with LD granted 50% ET, using ADHD and mental illness (e.g., anxiety, depression) groups as clinical comparisons. Findings indicated that over two-thirds of tests completed by students with LD, ADHD, or mental illness were completed within the time given in the classroom.

Spenceley and Wheeler (2016) examined the amount of ET used by students with varying disabilities, including cognitive, sensory, physical, and medical disorders. Of tests taken with 50% ET by students with LD or ADHD, large percentages (66% and 58%, respectively) were completed within standard time. For students with Psych disorders, 39% of tests were completed within standard time. Of tests taken by students with LD with 100% ET, 61% were completed within standard time, and over 80% were finished within 50% ET. Of tests taken by students with ADHD and Psych disabilities, 36% and 43% were completed within the standard time, respectively. Seventy percent for both groups were completed within 50% ET.

Sokal and Vernette (2017) also examined the amount of ET used by students, but did not break down the findings by disability type or amount of ET granted. Within their findings, 36% of tests were completed within the standard time provided in the classroom, and 84% of tests were completed with less than 50% ET. The authors also evaluated the use of ET as it related to course level. Students used more time on tests for third-level courses relative to first-level courses, and maintained the increase between year three and year four.

Overall, the studies suggested that the majority of students with ADHD, LD, or Psych disorders who are granted ET do not use the full amount of time allotted, and frequently use no ET at all. Authors concluded that smaller increments of ET (e.g., 25%) should be considered to ensure equal access to SWDs while maintaining fairness to those not receiving ET (Holmes & Silvestri, 2019; Spenceley & Wheeler, 2016).

**Current Study**

In the current study, the amount of ET used during tests taken by college students with LD, ADHD, and/or Psych was investigated with the objective of determining if the amounts of ET granted were sufficient for students to fully access their tests or if it was common that too little or even too much time was granted. The focus of the study was test completion, as it implies full access to a test, and not test outcome, as accommodations are intended to be outcome neutral. Whereas much has been learned about ET use over the past few years, several issues remain undetermined. First, the use of ET by students with comorbid cognitive and psychiatric conditions has yet to be evaluated. Spenceley and Wheeler (2016) included a multiple disabilities group, but the disabilities included physical and sensory disorders in addition to cognitive and psychiatric disorders. Investigating comorbid cognitive and psychiatric disorders is warranted due to the common comorbidities among the disorders of interest (Anastopoulos et al., 2018; Kessler et al., 2006) and the potential for an incremental increase in functional impact (Angold et al., 1999). Whereas it would seem intuitive that experiencing symptoms associated with multiple disorders would result in a need for greater time than those with single disabilities, this question has not been evaluated empirically. Second, the impact of course level has only been evaluated broadly, with findings reported for SWDs as a whole (Sokal & Vernette, 2017). Based on their findings that students used more ET as they advanced in college, Sokal and Vernette speculated that there could be a positive correlation between increasing course levels and difficulty of exams, which in turn might result in the need for additional time used to complete exams. Further examination into how year in school impacts time used to complete exams is warranted. Additionally, the impact of the potential interaction between year in school and disability type on time used to complete exams remains undetermined.

The current study attempted to replicate and extend the findings of Holmes and Silvestri (2019), Spenceley and Wheeler (2016), and Sokal and Vernette (2017). The use of ET by students with ADHD,
LD, and Psych disorders that were granted a 50% ET accommodation was investigated. Unlike previous investigations, groups with multiple disorders were included to examine the potential confounding effect on ET used. Additionally, ET use was evaluated for each disability group as a function of year in school. The specific research questions were as follows:

1. Of tests taken with ET, what is the distribution of disability type and year in school?
2. Of the ET allotted for tests, how much is used? Does the amount of ET used vary by disability type or year in school?
3. Does the ET used by students with comorbid disorders exceed the ET used by students with only one disorder?

Method

Sample

The sample was composed of 2,227 tests taken with 50% ET by students who came to a university disability services office during the spring semester of 2018. The tests included midterms, but not final exams due to a university-prescribed duration for finals that may not match actual exam length. Only undergraduate course tests taken by undergraduate students were included. Tests for which the standard time allotted was < 30 min were removed, as were tests on which students worked for < 10 min. The standard time for the remaining tests ranged from 30 to 210 min ($M = 72.79$, $SD = 29.11$). All tests administered with ET occurred in a low-distraction environment ($\leq 8$ students; 93%) or private room (7%). Use of stop-the-clock breaks was the next most common accommodation (11%). Use of other accommodations (e.g., access to a word processor, speech-to-text technology) was relatively infrequent ($\leq 3$% of tests per accommodation).

The dataset used for the study did not include case numbers, precluding determination of the exact number of students who took the tests. Although the variables of interest related to the tests themselves, and not to students, it was important to ensure that the tests were not all taken by a small number of students. To address this issue, the number of students was estimated using the available categorical variables (e.g., year in school, major, primary and secondary disability type) to identify all possible unique multivariate groups. The resulting number was 475, with each unique group associated with an average of 4.69 tests ($SD = 3.36$). Whereas it remained possible that the number of unique groups did not represent the precise number of students, the method used established the minimum number of students taking the tests. As a result, the number of students taking the tests in the total sample, as well as in each disability group, was at least as large as the sample sizes reported. Because a greater number of students would only improve the representativeness of the sample, the approach was deemed appropriate.

For the students taking the tests, eligibility for disability services and diagnostic classifications were determined by a team of three disability service professionals (DSPs) who reviewed submitted documentation against guidelines established by the governing university system (University System of Georgia, 2015). The guidelines for the LD category (estimated $n \geq 77$ students, $M = 4.38$ tests, $SD = 3.42$) required a diagnosis from a qualified evaluator, an educational history consistent with LD, substantially limited (i.e., standard score < 90) academic achievement skills (e.g., reading decoding, fluency, and/or comprehension), and a cognitive/linguistic processing deficit meaningfully associated with the identified academic limitation. The guidelines for the ADHD category (estimated $n \geq 165$, $M = 5.34$ tests, $SD = 3.48$) required a diagnosis of ADHD based on criteria from the Diagnostic and Statistical Manual of Mental Disorders - Fourth Edition, Text Revision (DSM-IV-TR; American Psychiatric Association [APA], 2000) or - Fifth Edition (DSM-5; APA, 2013) depending on when the diagnosis was made, evidence of clinically significant inattention and/or hyperactivity-impulsivity symptoms prior to the age of 12 and currently, corroborated by self-reported symptoms by an independent informant, and evidence of significant functional impairment in the academic setting. The guidelines for the Psych category (estimated $n \geq 62$, $M = 4.19$ tests, $SD = 3.13$) required a diagnosis based on DSM-IV-TR or DSM-5 criteria, a description of history, current symptoms, and severity of the disorder, and evidence of significant functional impairment in the academic setting. In all cases, diagnoses and impairment were required to have been determined or reconfirmed within the previous three years. In the case of comorbid disorders, the guidelines for all disorders were considered (LD/ADHD estimated $n \geq 55$, $M = 4.05$ tests, $SD = 3.18$; LD/Psych estimated $n \geq 17$, $M = 4.59$ tests, $SD = 2.29$; ADHD/Psych estimated $n \geq 85$, $M = 4.62$ tests, $SD = 3.43$; LD/ADHD/Psych estimated $n \geq 14$, $M = 3.93$ tests, $SD = 3.36$). Eligibility for the ET accommodation was determined by a DSP via an interactive process with the student while considering available documentation, history of accommodation usage, and current functional limitations. Tests taken by individuals with any type of cognitive, linguistic, developmental, or physical disability beyond...
LD, ADHD, and/or Psych disorders (e.g., depression, anxiety) were excluded.

Of the ADHD diagnoses represented in all groups (e.g., ADHD and comorbid groups), most were inattentive (44.85%) or unspecified (29.19%) types. Of the LD diagnoses represented in all groups, reading disorder was most frequent (34.30%), followed by LD diagnoses impacting multiple achievement areas (e.g., reading and math; 29.97%). Of the Psych disorders represented in all groups, anxiety disorder was the most frequent (48.22%), followed by comorbid Psych disorders (36.39%). Year in school was based on credit hours earned. The variable was reduced to two levels (i.e., underclassmen, upperclassmen) to address small sample size, reduce the number of statistical comparisons, and allow more parsimonious interpretation.

Procedure

The study was authorized by the institutional review board of the researchers’ university and conducted in a manner consistent with its principles. Data were collected from archival records stored by the disability services office at a large research university in the southeast United States. Variables were coded for each test administered as a part of standard procedure for the monitoring of tests administered at the site. Variables included disability type, year in school, major, standard time allotted for the test, ET allotted for the test, time used to complete the test, and other accommodations used. Time used to complete a test was determined using the barcode scanning function of test management software that recorded the precise times when a student was seated for the test and when the student turned in the test. As in previous studies (Sokal & Vermette, 2017), the ET variable was calculated by dividing the time used to complete the test by the standard time allotted for the test.

Analyses

The distributions of tests across disability type and year in school were analyzed using chi-square and logistic regression. The amount of ET used was evaluated by disability type and year in school using two-way analysis of variance (ANOVA) and post hoc comparisons. Cohen’s $d$ was calculated to estimate effect size where appropriate, with .2, .5, and .8 indicative of small, medium, and large effect sizes, respectively (Cohen, 1992). Finally, because ET is granted in intervals, most commonly 50% of standard time, the percentages of tests completed within increments of ET were analyzed using descriptive statistics. As in Spenceley and Wheeler (2016), a categorical variable was created to specify the increments of ET, including standard %, 1–25%, 26–50%, and >50%. Percentages of tests completed within each interval were calculated as a function of disability type and class level.

Results

Distribution of Disability Category and Year in School

Table 1 reports the distribution of tests taken with ET by disability category and year in school. Significantly more tests were taken by upperclassmen (75.4%) than by underclassmen (24.6%), $\chi^2 (1) = 574.39, p < .001$. The distribution of disability categories was not equal, $\chi^2 (6) = 1452.53, p < .001$. To evaluate relative sizes, 21 pairwise chi-square comparisons were conducted, with alpha set to .002 (.05/21) to minimize the chance of Type I error. Findings revealed that ADHD was the largest group, followed by ADHD/Psych and LD (equivalent), Psych and LD/ADHD (equivalent), and LD/Psych and LD/ADHD/Psych (equivalent).

To evaluate the distribution of disability category as a function of year in school, logistic regression was used to predict year in school from disability category. The omnibus analysis was significant, $\chi^2 (6) = 31.87, p < .001$, indicating statistically significant differences in the percentages of tests in each disability group by year in school. With alpha set at .007 (.05/7), post hoc comparisons indicated a significantly higher percentage of upperclassmen in the Psych group relative to the ADHD/Psych group, ADHD group, and the LD/ADHD group.

Time Used to Complete Tests as a Function of Disability and Year in School

In the next analyses, the time used to complete tests was evaluated by disability category and year in school when 50% ET was granted. The findings are reported in Table 2. Tests completed used 14% ET ($SD = .41$) on average. A two-way ANOVA with disability category, year in school, and their interaction as independent variables was conducted. Analysis of the assumptions associated with two-way ANOVA revealed that the data did not pass Levene’s test of homogeneity of variance, $W(13, 2213) = 2.13, p = .01$. As a result, the weighted least squares approach was used to adjust for the heterogeneity of variance in the different groups of test-takers (Kutner et al., 2005). The approach weights each point by one over the variance of the outcomes in the class level/disability group. The weighting allowed groups with greater variance to be treated as providing less precise information about the average outcome. The weight-
ed least squares approach does not change summary statistics or residuals, but standard errors are adjusted. Weights for the observations from each group are available upon request from the first author.

Results of the two-way weighted least squares ANOVA indicated that the interaction between disability category and year in school was not significant, $F(6, 2213) = 0.530, p = .786$. Significant group differences were identified for year in school, $F(1, 2213) = 5.496, p = .019$, indicating that upperclassmen took significantly more time to complete tests than underclassmen; however, the effect size was small ($d = .12$). The ANOVA for disability was also significant, $F(6, 2213) = 9.496, p = .001$. Bonferroni-adjusted post hoc comparisons ($0.05/21 = .002$) indicated that the LD/ADHD/Psych group required significantly less time than all other groups except the LD/Psych group. Effects sizes were large for comparisons with the ADHD and LD/ADHD groups (both $d = .84$) and medium with the ADHD/Psych ($d = .66$), LD ($d = .48$), and Psych ($d = .61$) groups. The LD group also required significantly less time than the ADHD and LD/ADHD groups, though effect sizes were small ($d \leq .34$).

Percentages of Tests Completed Within Increments of Standard Time

In the next analyses, the percentages of tests completed within increments of ET when 50% ET was allotted were analyzed. The findings are reported in Table 3. Of all tests taken with 50% ET, 37.27% were completed within standard time and 54.87% were completed within 25% ET. Over 22% of tests were completed using more than 50% ET.

The percentage of tests completed within standard time by disability ranged from 31.90 (ADHD) to 47.77 (LD). The exception was for the LD/ADHD/Psych group, for which 67.27% of tests were completed within standard time. Cumulatively, the percentage of tests completed using >50% ET was substantial for all but the LD/ADHD/Psych group (1.82%). Of all tests taken with 50% ET, the percentages of tests completed by underclassmen relative to upperclassmen during standard time was separated by just 4.06 percentage points (40.33% for underclassmen and 36.27% for upperclassmen) and were virtually

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Table 1

Distribution of Tests Taken with 50% Extended Time by Disability and Year in School

<table>
<thead>
<tr>
<th>Disability</th>
<th>Underclassmen</th>
<th></th>
<th>Upperclassmen</th>
<th></th>
<th>Total</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>$n$</td>
<td>%</td>
<td>$n$</td>
<td>%</td>
<td>$n$</td>
<td>%</td>
</tr>
<tr>
<td>ADHD</td>
<td>240</td>
<td>27</td>
<td>641</td>
<td>$73_b$</td>
<td>881$^a$</td>
<td>40</td>
</tr>
<tr>
<td>ADHD/Psych</td>
<td>104</td>
<td>26</td>
<td>289</td>
<td>$74_b$</td>
<td>393$^b$</td>
<td>18</td>
</tr>
<tr>
<td>LD</td>
<td>67</td>
<td>20</td>
<td>270</td>
<td>$80_ab$</td>
<td>337$^b$</td>
<td>15</td>
</tr>
<tr>
<td>Psych</td>
<td>35</td>
<td>13</td>
<td>225</td>
<td>$87_a$</td>
<td>260$^c$</td>
<td>12</td>
</tr>
<tr>
<td>LD/ADHD</td>
<td>66</td>
<td>30</td>
<td>157</td>
<td>$70_b$</td>
<td>223$^c$</td>
<td>10</td>
</tr>
<tr>
<td>LD/Psych</td>
<td>23</td>
<td>29</td>
<td>55</td>
<td>$71_ab$</td>
<td>78$^d$</td>
<td>4</td>
</tr>
<tr>
<td>LD/ADHD/Psych</td>
<td>13</td>
<td>24</td>
<td>42</td>
<td>$76_ab$</td>
<td>55$^d$</td>
<td>2</td>
</tr>
<tr>
<td>Total Tests</td>
<td>548</td>
<td>25</td>
<td>1,679</td>
<td>$75*$</td>
<td>2,227</td>
<td>100</td>
</tr>
</tbody>
</table>

Note. ADHD = Attention-Deficit/Hyperactivity Disorder, Psych = Psychiatric Disorder, LD = Learning Disability. Underclassmen and upperclassmen percentages sum across rows; total percentages sum down the column. Total $n$ column superscripts refer to the distribution of disability categories. Proportions sharing a common superscript are not statistically different at alpha $= .002 (.05/21)$. Upperclassmen % column subscripts refer to the distribution of disability categories as a function of year in school. Proportions sharing a common subscript are not statistically different at alpha $= .007 (.05/7)$.

* The proportion of tests taken by upperclassmen was significantly greater than the proportion taken by underclassmen at the .05 level.
**Distribution of Disability Category and Year in School**

ADHD was the most common disability type, followed by ADHD/Psych and LD. These findings were only slightly different from those of Spenceley and Wheeler (2016), who found LD to be the most common category, followed by ADHD. Regarding year in school, the vast majority of tests (75%) were taken by upperclassmen (as classified by credits earned) in the current study. Additional analyses revealed that only 3.46% of the 2,227 total tests were taken by first-year students. Whereas the current study was not designed to investigate the proportion of eligible students who used the ET accommodation and a number of varied reasons could account for this low percentage, the finding was surprisingly low and is worthy of further investigation.

**Table 2**

<table>
<thead>
<tr>
<th>Disability</th>
<th>Underclassmen</th>
<th></th>
<th>Upperclassmen</th>
<th></th>
<th>Total</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>M (SD)</td>
<td>n</td>
<td>M (SD)</td>
<td>n</td>
<td>M (SD)</td>
</tr>
<tr>
<td>ADHD</td>
<td>240</td>
<td>1.15 (0.44)</td>
<td>641</td>
<td>1.21 (0.38)</td>
<td>881</td>
<td>1.19 (0.40)</td>
</tr>
<tr>
<td>ADHD/Psych</td>
<td>104</td>
<td>1.05 (0.41)</td>
<td>289</td>
<td>1.16 (0.41)</td>
<td>393</td>
<td>1.13 (0.41)</td>
</tr>
<tr>
<td>LD</td>
<td>67</td>
<td>1.05 (0.41)</td>
<td>270</td>
<td>1.06 (0.39)</td>
<td>337</td>
<td>1.06 (0.40)</td>
</tr>
<tr>
<td>Psych</td>
<td>35</td>
<td>1.09 (0.39)</td>
<td>225</td>
<td>1.12 (0.41)</td>
<td>260</td>
<td>1.11 (0.41)</td>
</tr>
<tr>
<td>LD/ADHD</td>
<td>66</td>
<td>1.18 (0.46)</td>
<td>157</td>
<td>1.20 (0.40)</td>
<td>223</td>
<td>1.20 (0.42)</td>
</tr>
<tr>
<td>LD/Psych</td>
<td>23</td>
<td>0.98 (0.34)</td>
<td>55</td>
<td>1.11 (0.40)</td>
<td>78</td>
<td>1.07 (0.38)</td>
</tr>
<tr>
<td>LD/ADHD/Psych</td>
<td>13</td>
<td>0.83 (0.26)</td>
<td>42</td>
<td>0.89 (0.36)</td>
<td>55</td>
<td>0.88 (0.34)</td>
</tr>
<tr>
<td>Average</td>
<td>548</td>
<td>1.10 (0.43)</td>
<td>1679</td>
<td>1.15* (0.40)</td>
<td>2227</td>
<td>1.14 (0.41)</td>
</tr>
</tbody>
</table>

Note. ADHD = Attention-Deficit/Hyperactivity Disorder, Psych = Psychiatric Disorder, LD = Learning Disability. Total M(SD) column superscripts refer to post hoc mean comparisons for disability category. Means sharing a common superscript are not statistically different at alpha = .002 (.05/21).

* The difference between time used/standard time for underclassmen and upperclassmen was significant at the .05 level.

identical for tests completed within 25% ET and >50% ET.

**Discussion**

The purpose of the current investigation was to evaluate the use of the ET accommodation at the postsecondary level. Specifically, the authors sought to determine the number of tests taken with 50% ET and the amount of ET used during those test administrations, with both variables considered in relation to disability type and year in school.

**Time Used to Complete Tests as a Function of Disability and Year in School**

Consistent with previous research (Holmes & Silvestri, 2019; Sokal & Vermette, 2017; Spenceley & Wheeler, 2016), the average amount of time used on tests taken with ET was well below the amount granted. For tests taken with 50% ET, the average ET
Table 3

Percentage of Tests Completed Within Increments of Test Time Allotted When Granted 50% Extended Time

<table>
<thead>
<tr>
<th>Disability</th>
<th>Year</th>
<th>Standard %</th>
<th>1-25%</th>
<th>26-50%</th>
<th>&gt;50%</th>
</tr>
</thead>
<tbody>
<tr>
<td>LD</td>
<td>Underclassmen</td>
<td>47.76</td>
<td>16.42</td>
<td>14.93</td>
<td>20.90</td>
</tr>
<tr>
<td></td>
<td>Upperclassmen</td>
<td>47.78</td>
<td>19.63</td>
<td>16.67</td>
<td>15.93</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>47.77</td>
<td>18.99</td>
<td>16.32</td>
<td>16.91</td>
</tr>
<tr>
<td>ADHD</td>
<td>Underclassmen</td>
<td>35.42</td>
<td>16.25</td>
<td>20.83</td>
<td>27.50</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>31.90</td>
<td>16.12</td>
<td>25.31</td>
<td>26.67</td>
</tr>
<tr>
<td>Psych</td>
<td>Underclassmen</td>
<td>34.29</td>
<td>40.00</td>
<td>11.43</td>
<td>14.29</td>
</tr>
<tr>
<td></td>
<td>Upperclassmen</td>
<td>36.89</td>
<td>21.33</td>
<td>21.78</td>
<td>20.00</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>36.54</td>
<td>23.85</td>
<td>20.38</td>
<td>19.23</td>
</tr>
<tr>
<td>LD/ADHD</td>
<td>Underclassmen</td>
<td>36.36</td>
<td>13.64</td>
<td>22.73</td>
<td>27.27</td>
</tr>
<tr>
<td></td>
<td>Upperclassmen</td>
<td>31.85</td>
<td>18.47</td>
<td>24.84</td>
<td>24.84</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>33.18</td>
<td>17.04</td>
<td>24.22</td>
<td>25.56</td>
</tr>
<tr>
<td>LD/Psych</td>
<td>Underclassmen</td>
<td>56.52</td>
<td>17.39</td>
<td>17.39</td>
<td>8.70</td>
</tr>
<tr>
<td></td>
<td>Upperclassmen</td>
<td>40.00</td>
<td>18.18</td>
<td>21.82</td>
<td>20.00</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>44.87</td>
<td>17.95</td>
<td>20.51</td>
<td>16.67</td>
</tr>
<tr>
<td>ADHD/Psych</td>
<td>Underclassmen</td>
<td>42.31</td>
<td>18.27</td>
<td>19.23</td>
<td>20.19</td>
</tr>
<tr>
<td></td>
<td>Upperclassmen</td>
<td>35.64</td>
<td>15.92</td>
<td>23.18</td>
<td>25.26</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>37.40</td>
<td>16.54</td>
<td>22.14</td>
<td>23.92</td>
</tr>
<tr>
<td>LD/ADHD/Psych</td>
<td>Underclassmen</td>
<td>84.62</td>
<td>0.00</td>
<td>15.38</td>
<td>0.00</td>
</tr>
<tr>
<td></td>
<td>Upperclassmen</td>
<td>61.90</td>
<td>16.67</td>
<td>19.05</td>
<td>2.38</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>67.27</td>
<td>12.73</td>
<td>18.18</td>
<td>1.82</td>
</tr>
</tbody>
</table>

Note. ADHD = Attention-Deficit/Hyperactivity Disorder, Psych = Psychiatric Disorder, LD = Learning Disability.
used was 14%, a finding consistent with that of Sokal and Vermette (17%; 2017), as well as with analogue studies investigating the time required for SWDs to access a similar number of items as controls (4-14%, Cahalan-Lautisius et al., 2006; 14%, Spenceley et al., 2020). The findings also aligned with previous studies (Holmes & Silvestri, 2019; Spenceley & Wheeler, 2016) in that notable percentages of students used more than the ET allotted to them. In all, the evidence suggested that too much ET is often granted, students sometimes use more ET than they are allotted, and current methods for determining the amount of ET required to access a test are inadequate.

Additionally, no consistent pattern emerged to suggest a connection between disability type and amount of time used. First, despite some statistically significant differences in the amounts of test time used, the majority of effect sizes were small (Cohen, 1992), and the only large effects occurred when comparing disability categories with the category with the lowest mean time used (i.e., LD/ADHD/Psych). Second, a rank ordering of the disability categories by the mean amount of time used suggested no discernable pattern. When ranked from most to least time used when granted 50% ET, ADHD was associated with the first, second, and third positions (i.e., LD/ADHD, ADHD, ADHD/Psych); however, it was also associated with the least time used (i.e., LD/ADHD/Psych). Third, within each disability category, the range of time used was quite large. For tests taken with 50% ET, the percentage of time used ranged from an average low of 20% of standard time to an average high of over double time (104%).

The large range of ET used was further evident in the findings conducted using ET as a categorical variable. In the results, it was common for tests taken with ET to be completed within the standard time or with only a fraction of allotted ET. Of all tests taken with 50% ET, 37% were completed within standard time, and 55% were completed within 25% ET. Previous investigations have revealed similar findings, though often demonstrating need for even less ET (Holmes & Silvestri, 2019; Spenceley & Wheeler, 2016).

Finally, previous research has found that upperclassmen generally use more time on tests than underclassmen (Sokal & Vermette, 2017). The findings in the present study revealed the same pattern, though the effect size was small and unconvincing (d = .12). As a result, it remains unclear if year in school is associated with increasing exam difficulty and therefore need for more ET, as speculated by Sokal and Vermette.

Extended Time Used by Students with Comorbid Disorders

The findings suggested that individuals with multiple non-apparent disabilities generally do not require greater amounts of ET than individuals with single disabilities. When ranking categories by ET used from most to least, comorbid presentations were ranked one, three, five, and seven. To the authors’ knowledge, no previous studies have investigated the impact of multiple non-apparent conditions on the use of ET; however, individuals with multiple disabilities, including comorbid manifestations of cognitive, psychological, physical, visual, and medical conditions, used the most time when granted 100% ET in one previous study (Spenceley & Wheeler, 2016), though they also required less than standard time when granted 50% ET.

Limitations

The study findings must be considered within the context of several limitations. First, whereas the overall sample size was large, it was drawn from tests administered during one semester at a single, large university, limiting generalizability. Second, the numbers of students comprising the LD/Psych and LD/ADHD/Psych groups were relatively small (estimated n ≥ 17 and 14, respectively), and associated findings should be interpreted with caution. For example, the mean time used for tests administered with 50% ET was surprisingly low for the LD/ADHD/Psych group, an anomaly potentially due to the small sample size. Third, tests were not limited to a specific subject or response format, precluding specific recommendations related to those variables. Fourth, all tests were administered with ET in a reduced distraction environment (rooms with ≤ 8 students) or private room. As a result, the effects of an alternative testing environment on use of ET could not be uncoupled. Finally, the investigation did not incorporate a control group, preventing comparisons with tests taken under standard conditions.

Implications and Recommendations

Appropriateness of the ET Durations Provided

In the current study, the amounts of ET granted often seemed to have little relation to the amounts of ET students actually needed to access tests. Historically, there has been little empirical evidence to inform how much ET would allow SWDs to attempt a similar number of items as students without disabilities, a scenario that would suggest equal access. Though the number of items attempted by students without disabilities on these tests were not determined, 55% of the tests in this study were completed within 25%
ET, indicating access to the entirety of the test. As such, the findings suggest that a smaller amount of ET, such as 25%, would be sufficient for full access on most tests taken by students with non-apparent disabilities in the absence of a clearly severe condition. These findings converge with those of other studies which have concluded that 25% ET would provide equal access for all test-takers, including ET investigations of reading comprehension and college LD (Lewandowski, Cohen, & Lovett, 2013); the SAT and high school LD and ADHD (Cahalan-Laitusis et al., 2006); and course tests and college LD, ADHD, and Psych (Holmes & Silvestri, 2019; Spenceley & Wheeler, 2016). As a result, offices of disability services have accumulating research to support the use of 25% ET as an evidence-based practice when deemed appropriate. Recognizing that 25% ET is sufficient in a large portion of cases, DSPs could also consider tracking ET duration use and working with students to systematically reduce reliance on unnecessary ET (Slaughter et al., 2020). For instance, Sokal and Vermette (2017) recommended that DSPs meet annually with students to reevaluate the need for ET.

**The Role of Disability Type When Determining ET Need**

The findings indicated that, in the absence of more informative data, it would be ill-advised to use a diagnostic label—or the number of diagnostic labels—to estimate the amount of ET an individual might require for equal access to a test. As noted in the *DSM-5*, “impairments, abilities, and disabilities vary widely within each diagnostic category” (APA, 2013, p. 25). It is for these reasons that ADA regulations require that accommodation requests be considered on a case-by-case basis (Nondiscrimination on the basis of disability by state and local governments, 2016). It is notable that there have been recommended practices proposed that associate a diagnosis with an automatic ET accommodation (see Colker et al., 2015). The findings suggest that a diagnosis itself is insufficient to substantiate a need for ET or inform a needed ET duration. As a result, accommodations should be determined via a case-by-case analysis of the severity of an individual’s limitations and interactions with the non-essential demands of the test.

DSPs should follow recommended practices for determining ET duration, which include evaluation of measures of academic fluency (e.g., timed tests of reading comprehension), consideration of the rate of completion of other academic tasks, and consultation with those who have observed the student’s test-taking behavior (Lovett & Lewandowski, 2015). The amounts of ET granted to SWDs likely would have greater precision if more emphasis was placed on evidence of impairment relative to most people in the general population than on diagnoses, which are frequently based on symptoms in the absence of impairment (e.g., Sparks & Lovett, 2013; Weis et al., 2019).

**Use of ET in First-Year Students**

The finding that only three percent of tests taken with ET were taken by first-year students (based on credits earned) was striking. A number of benign factors could account for this finding. For example, some students begin their postsecondary education having already earned some college credits. Because the classification was based on credits earned, some portion of students in their first year on campus may have been classified as second-year students. Additionally, it could be that first-year students simply take fewer tests than other students, the test formats are less complex (e.g., multiple choice versus a combination of multiple choice, application, and constructed response), or instructors of first-year courses are more lenient with the time allotted for tests.

It is also possible, however, that factors significant to DSPs played a role. First-year students eligible for disability services may have a lack of knowledge regarding how to access services, perceive a hostile campus climate, or have a desire to be free of the disability label, all of which have been found in previous studies (Lightner et al., 2012; Slaughter et al., 2020). Each of these would be concerning and relevant to DSPs. In all, the findings suggest the possibility that first-year students may under-utilize disability services. Given that appropriate supports and accommodations have been shown to be related to postsecondary academic success for SWDs (Lightner et al., 2012), DSPs are encouraged to employ proactive outreach to first-year students and increase collaboration between secondary transition teams and postsecondary institutions.

**Further Study**

The findings suggested several areas for future research. First, it would be informative to investigate how students are using ET. For example, students with ADHD have been found to be similar in test-taking speed when compared to those without disabilities in analogue studies (Lewandowski, Gathje, et al., 2013), yet ADHD was the disability most frequently associated with ET use in the current study. It is possible that—given the real stakes of the tests in the current study—students delayed leaving to wrestle with indecisiveness, check work, or hope that some answers might come to them even though they had responded to all test items. Such occurrences would be
unlikely in analogue studies. It remains unclear, then, how the time was being used and whether it was necessary or beneficial. Second, research suggests that faculty generally are willing to provide accommodations (Murray et al., 2008); however, the frequency that they consider constructs such as test-taking speed when developing tests has not been evaluated, nor has the degree to which they perceive accommodations as compromising assessment of those constructs. Third, future similar studies are encouraged to investigate the number of SWDs who decline to use their ET, instead taking tests with classmates. Fourth, findings revealed that a substantial number of tests were completed after the granted ET expired. This finding is consistent with those of previous studies (Holmes & Silvestre, 2019; Spenceley & Wheeler, 2016), suggesting the occurrence may not be unusual. Further investigation into the frequency, causes, and ramifications of allowing students more ET than they are granted is needed. Fifth, further investigation into why only three percent of tests administered with ET were taken by first year students would be useful. Finally, ET will likely remain a frequently used accommodation for the foreseeable future. The extant research on predictors of ET need is meager (Ofiesh, 2015), and studies are needed to identify additional variables and methods to enhance ability to predict how much ET is needed to provide equal access for SWDs.

References


**About the Authors**

Will Lindstrom received his Ph.D. in educational psychology from the University of Georgia (UGA). He is currently the director of the UGA Regents’ Center for Learning Disorders, an evaluation, training, and research center dedicated to serving postsecondary students with learning-related disabilities. He is licensed as a psychologist in Georgia and Virginia. His primary research interests relate to the assessment and documentation of postsecondary learning-related disabilities. He can be reached by email at: wlindstr@uga.edu.

Jennifer H. Lindstrom received her Ph.D. in special education from the University of Georgia (UGA). She is currently an associate professor in the Department of Communication Sciences and Special Education at UGA. Her research focuses on causes and treatment of dyslexia and other learning disabilities, issues surrounding the provision of accommodations to students with dyslexia and other learning disabilities, and early literacy with a focus on teacher training and the use of research-based methodologies for improving student performance. She can be reached by email at: jhl@uga.edu.

Mary Hall Slaughter is currently a doctoral student in the School Psychology program at the University of Georgia. Her research interests focus on the assessment of ADHD, dyslexia, and psychiatric disorders, and the determination of extended time testing accommodations for these students. She can be reached by email at: mhds@uga.edu.

Trisha Barefield received her M.Ed. from the Institute of Higher Education at the University of Georgia (UGA) and is currently pursuing her Ph.D. in Learning, Leadership, and Organization Development at UGA. She has worked in disability services for eight years and currently serves as Associate Director for University Testing Services and Accommodated Testing at UGA. Her research interests center around learning and organization within higher education. She can be reached by email at: tatonge@uga.edu.

Erin Williams Benson received both her B.A. degree in anthropology and an MPA from the University of Georgia (UGA). She has worked in student affairs for the past 15 years and currently serves as the Director of the Disability Resource Center at UGA. She can be reached by email at: eew@uga.edu.
Invisible Chronic Illness in Female College Students

Danielle Barber¹
James L. Williams¹

Abstract

This study examined how female students negotiate the experience of college while living with an invisible chronic illness. Four research questions were explored. Quantitative data, through the use of online surveys, were collected from 105 female students living with a chronic illness enrolled at a medium-sized university in the Southwestern U.S. Results indicated that the majority of participants view their illness as a serious condition that has impacted their life. The majority of respondents reported that they feel capable of completing college, obtaining a job, and view themselves as a person of worth; however, nearly all respondents reported they have avoided social situations in college because of their chronic illness. The majority of participants indicated they accept their chronic illness diagnosis and about half reported that they engage in healthy coping behaviors. We discuss implications of the findings for administrators and disability support services and suggest additional research.

Keywords: chronic illness, disability, higher education, females

Chronic illnesses such as multiple sclerosis, lupus, endometriosis, fibromyalgia, and many more have the potential to disrupt an individual’s sense of self, construction of self, and role performance, especially while attending college (Dennison et al., 2011; Werner et al., 2004). More importantly, many of the symptoms of chronic illnesses follow a relapsing-remitting pattern and are not always easily apparent to others. Some hidden symptoms and less visible symptoms of chronic illnesses include chronic pain, fatigue, inflammation, bowel and bladder disturbances, and limitations in mobility, just to name a few (Vassilev et al., 2014). Unfortunately, stigma often derives from issues of legitimacy related to the visibility of chronic disease symptoms because the symptoms might not be discernible to others (Green et al., 2005). When symptoms cannot be seen, relatives, friends, employers, and colleagues are unlikely to understand the seriousness of the illness and how it impacts the life of the person. Even worse, once individuals finally decide to disclose their chronic illness to those outside of their family, they are often not believed by others (Vickers, 2017), and some individuals have reported that others have accused them of faking or making up their illness to avoid obligations or gain special advantages (Green, et al., 2005). Lack of disclosure and efforts to conceal their disability status often result in increased anxiety within this population, which can, in turn, exacerbate chronic illness symptoms (Adams & Proctor, 2010; Livneh et al., 2001; Vickers, 2017).

The process of psychosocial adjustment to college as a female with a hidden chronic illness involves many factors such as stigma management, disclosure, coping strategies, social support, and identity reconstruction (Davis, 2006). Women, more often than men, face stigma, shame, blame, and credibility issues when disclosing their invisible chronic illness within various institutions (Werner et al., 2004). This study examines how female students in higher education negotiate the experience of college while living with a hidden chronic illness. More specifically, this study provides knowledge and insight about a unique population and the way this population navigates and experiences the reality of living with a hidden chronic illness while attending college.

Four research questions are explored in this study: How do female students feel about their chronic illness in general? How has the identity of female students living with an invisible chronic illness been impacted by attending college? How do fe-
male students with an invisible chronic illness adjust to college and cope with their chronic illness? How do female college students with an invisible chronic illness perceive the effectiveness of accommodations provided by individual instructors, Disability Support Services (DSS), and the university overall? Data, using self-report surveys, were collected from female college students located at a medium-sized (approximately 16,000 students) state university in the Southwestern U.S. who are living with a hidden chronic illness. The survey used in this study collected data concerning each respondent’s attitudes and perceptions toward their experiences and identity as a female college student living with a hidden chronic illness, as well as their attitudes towards feeling included in day-to-day college life, whether or not they perceive that they have equal access to programs at their university, and their attitudes and perceptions towards social acceptance.

**Related Literature**

**Hidden Chronic Illness in Higher Education**

Students with chronic health problems are entering universities at numbers higher than ever before, and they face a number of unique challenges in the university (Korbel et al., 2011; Peña, 2014; Wodka & Barakat, 2006). Royster and Marshall (2008) contend that “the nation’s colleges and universities have yet to recognize the significance of this development and its implications for traditional faculty-student relationships, student support services, and the strict time structures that frame college life” (p. 120). Additionally, numerous studies have found that increases in stress contribute to increases in chronic illness symptoms and severity, as well as impaired immune system functioning (Matheny et al., 2005; Rawson et al., 1994; Vassilev et al., 2014). Transitioning to college includes many stressors. However, students with a chronic illness often face additional challenges during college, which might include attending numerous medical appointments, ongoing illness management, exacerbation of illness symptoms, and issues related to autonomy, all of which contribute to problems of attrition (Adams & Proctor, 2010; Moore, 2012; Wodka & Barakat, 2007). It is upsetting, to say the least, that many students, despite exhibiting outstanding academic abilities, end up with an academic history of incompletes, withdrawals, and failing grades because the structure of higher education has fallen short in providing an accessible environment for students with chronic illness (Royster & Marshall, 2008).

Due to the ableistic structure of higher education, students with chronic illness can be a source of frustration for instructors (Evans et al., 2017). This frustration partly comes from the fact that instructors are often faced with students of varying learning needs coupled with limited resources (Evans et al. 2017). Even though “students with disabilities must identify their own needs before colleges and universities will provide accommodations” (Adams & Proctor, 2010, p. 177), it is common for students with a chronic illness not to self-identify as having a disability because they do not view their chronic illness as a disability (Royster & Marshall, 2008). Additionally, due to the unpredictability of chronic illness symptoms, accommodations are unique to each student and require continuous adaptation, adjustment, negotiation, and arrangement in order to appropriately meet the needs of students with a chronic illness (Royster & Marshall, 2008). Adams and Proctor (2010) discovered that students who experienced a high degree of self-advocacy skills were found to be more successful in adapting to college life, which highlights the importance of self-advocacy skills for this population within higher education settings. However, the reality is that students with a chronic illness often lack self-advocacy skills, as well as the knowledge of how to address their chronic illness needs in a higher education environment (Royster & Marshall, 2008).

**Women Living with Chronic Illness**

Women are known to be affected by invisible chronic illness at higher rates than men (Åsbring & Närvänen, 2002; Werth et al., 2018). Women with invisible chronic illness constantly face judgment and questioning about whether or not their illness is legitimate or imaginary (Repetto et al., 2012.) In addition, women are repeatedly given a psychiatric label, which is now the modern form of female hysteria (Werner et al., 2004; Vickers, 1997). Research has indicated that women face stigma, shame, blame, and credibility issues when disclosing their invisible chronic illness within various institutions (Werner et al., 2004). Important to note, Clark pointed out in 2006 that women of color with invisible disabilities and chronic illnesses in higher education have yet to be studied. In most of the research on this topic, the majority of participants have been middle-class white women (Clark, 2006). This is troubling because African American women are affected by Lupus at higher rates than any other female ethnic group (Rosales and Person, 2003).

Women in patriarchal society are often viewed as “caretaker” and not “cared for” (Mintz, 2007). “In a culture that privileges only the white, male ‘able’
body as the ‘neutral’ and normative self, disability is both an emphatically particular embodied reality and a trope for disenfranchisement” (Mintz, 2007, p. 39). The study of disabilities has examined how some individuals with disabilities reclaim, redefine, and/or reframe their identity outside of the dominant paradigm of ableism (Clark, 2006). “What one understands of disability, femaleness, and identity is continually being unraveled and unwoven” (Mintz, 2007, p. 44). For those living with a chronic illness that is episodic or progressive in nature, identity and the ability to self-identify as disabled may need to be reworked repeatedly as symptoms emerge (Mintz, 2007; Davis, 2006).

Separation, as a component of felt stigma, occurs when individuals encounter numerous negative reactions from others which can result in depression and negative perceptions of the self (Evans et al., 2017; Green et al., 2005). Green et al. (2005) revealed that individuals with disabilities report losing their own sense of worth, sense of identity, and sense of being a whole person, all of which can lead to social isolation. “If the self we see reflected in the eyes of others is devalued, there is little incentive for social interaction” (Green et al. 2005, p. 210). Individuals with an invisible chronic illness actively attempt to manage felt stigma, either through rejection of a disabled identity or by embracing a disabled identity (Evans et al. 2017). For example, Riddell and Weedon (2014) found that some individuals with disabilities are beginning to embrace the political category of disability by lessening the negative image of disability and by focusing on ability and difference rather than disability and normalcy that comes from socially constructed environments.

**Chronic Illness as a Continual Disruptive Event**

As a founder in the field of chronic illness, Bury (1982) noted that constantly changing symptoms and life circumstances require constant adjustments on behalf of the person with a chronic illness and as such, the process of adjustment will be ongoing and changing. Additionally, there are disruptions in the everyday taken-for-granted assumptions in the individual’s plans for the future and a newly, ever-present, casted shadow of anxiety and uncertainty. Bury contended that these disruptions are crucial for sociologists to understand because they are powerful enough that “a fundamental re-thinking of the person’s biography and self-concept is involved” (p. 169). Indeed, Bury’s work on the chronic illness experience “suggests that the assault on identity for many people when they are unable to perform as usual can be profound” (Dyck & Jongbloed, 2000, p. 342).

**The British Social Model of Disability**

The British Social Model of Disability provides a perspective that is helpful to institutional organizations in understanding individuals with disabilities as well as individuals with invisible chronic illness. Invisible chronic illnesses meet criteria for disability defined by the United Nations, which suggests that a disabled persons’ ability to carry out daily living activities results in multiple hindrances to their financial and social circumstances (Jung, 2002); thus, the Social Model of Disability is an appropriate perspective to use in current understandings of invisible chronic illness. The Social Model of Disability posits that social structures fail to properly accommodate disabled individuals, which leads to oppressing this population (Clark, 2006; Olkin, 2002). Society largely views health and illness as a responsibility of the individual which should be managed through proper lifestyle choices (Vickers, 2017). Olkin (2002) outlines the importance for wider society to utilize this model and warns that it is imperative that society adopts the social model or else persons with disabilities will continue to be disadvantaged.

Structural conditions, such as the fact that higher education has been restructured to align more with a neoliberal agenda, has resulted in a system that values product over people (Jung, 2002). Current declines in economic conditions have resulted in a decline in the amount of funding and resources in disability services (Riddell & Weedon, 2014). By ignoring structural factors that oppress, separate, and hinder individuals with disabilities by fully participating in society, the focus remains on the individual as being defective (Clark, 2006).

**Invisibility**

Visibility of chronic illness poses unique challenges for students whose impairments are not readily visible when compared to students with visible impairments (Clark, 2006). Research should distinguish between the two because students with hidden or less visible impairments are likely to have vastly different experiences in higher education settings than students with impairments that are easily seen by others (Green, et al., 2005). People with invisible disabilities do not report experiencing pity and awkwardness in social interactions, but instead report higher levels of blame and separation due to misunderstandings and stigmas resulting in a variety of individual outcomes (Martz, 2003). Once a negative label from society is placed upon an individual, it is likely that the individual will experience additional hindrances that will interfere with their complete integration and acceptance into society, as well as interfere with the achievement.
of the individuals’ personal goals, such as acquiring a college degree (Seo & Chen, 2009).

The choice to conceal or disclose their disability status depends on weighing the costs and benefits of self-disclosing (Riddell & Weedon, 2014). A positive aspect of disclosing their disability status within the university is that the university can usually ensure students receive accommodations (Adams & Proctor, 2010; Vickers, 1997). Despite the advantages of disclosing their disability status, students often choose to hide their status and aim to pass as normal in an attempt to avoid stigma and discrimination (Åsbring & Närvänni, 2002; Moore, 2012; Riddell & Weedon, 2014; Vickers, 1997). There might be little motivation to disclose a chronic illness if others will not believe the illness or if the illness is highly stigmatized. Indeed, students report experiencing suspicion and lack of confidence from instructors after choosing to disclose their status (Riddell & Weedon, 2014) and choosing to disclose can be described as “damned if you do, damned if you don’t” (Moore, 2012, p. 208).

Often, in terms of deadline extensions and disability related absence accommodations, Disability Support Services offices leave these decisions up to the discretion of the instructor. Many students with a hidden chronic illness report being told by professors that they could not receive disability-related accommodations because this would not be fair to the other students (Jung, 2002). Due to strict attendance policies, cumulative absences will eventually force students to self-disclose their invisible chronic illness. Additionally, some illnesses may lead others to doubt a legitimate need for accommodations that may require frequent absences from class during acute episodes or exacerbations. Furthermore, students may then be reluctant to self-identify and request accommodations from faculty who may not see any obvious impairment” (Korbel et al., 2011, p. 19). Students might also be reluctant to disclose for fear of discrimination and fear that future employment prospects within the field of their studies will be impacted (Riddell & Weedon, 2014). For some individuals, choosing not to disclose is the most rational choice in a situation (Matthews, 2009).

It is important to note that one of the authors of this study is a current female college student living with hidden invisible illnesses. The author entered college with major depressive disorder, generalized anxiety disorder, and post-traumatic stress disorder. However, in the course of her college experience, she began to experience physical symptoms that first led to a misdiagnosis of multiple sclerosis then later to a diagnosis of fibromyalgia. The author approaches this research using her own personal experience while also recognizing that no two individual experiences are ever the same.

**Data and Methods**

Quantitative data, using self-report surveys, were collected from female college students living with a hidden chronic illness who were located at a state university in the Southwestern U.S. This study was approved as exempt by the university’s Institutional Review Board.

The online survey collected demographic information about the participants, which included each participant’s age, race, sex, ethnicity, socioeconomic status, marital status, and the number of years the participant has attended college. The sample includes both undergraduate and graduate female students who were, at the time of the study, enrolled at the university. A recruitment email was sent to all registered students at the university (at the time approximately 15,500 students), which included a full description of the study, as well as a URL link that students could click if they chose to complete the voluntary online anonymous survey. After the recruitment process was complete, participants had a one-month period to complete the survey. A total of 118 responses were obtained. After examination of the responses, the incomplete surveys were discarded, leaving 105 completed surveys, which were chosen for analysis.

The survey used in this study collected data concerning each respondent’s (a) attitudes toward and perceptions of their experiences and identity as a female college student living with a hidden chronic illness, (b) attitudes toward feeling included in day-to-day college life, (c) whether or not they perceive that they have equal access to programs at their University, and (d) their attitudes and perceptions towards social acceptance. Each item used a five-point Likert scale format. The survey used in this study contains a total of 72 questions and was pilot tested with a panel of three individuals before distribution. These three individuals were current or former graduate students who are living with a chronic illness. Items were revised for clarity as needed based on a review of the pilot test. A substantial number of the items came from previously validated instruments. Specifically, 24 of the 72 items came from previously validated instruments.

To measure participants’ coping and adjustment strategies, survey items 1-5 and 21 were drawn from COPE, which is a questionnaire developed to assess the different ways individuals respond to and manage stress (Carver et al., 1989). Additionally, items 8-9, 33, 35-36, which pertain to self-management of
chronic illness, were drawn from The Chronic Illness Resources Survey (Glasgow et al., 2000). In order to examine the impact chronic illness has on the identity of each participant, survey items 10-20 and 24 were taken from the Revised Illness Perception Questionnaire (Moss-Morris et al., 2002) and items 26 and 29 were taken from Rosenberg’s (1965) Self-Esteem Scale. The remaining items were created for the purposes of this survey.

Data analysis was completed with SPSS 25. Frequency distributions and contingency tables were used to examine trends and patterns in the responses and to address the research questions. To ensure accurate interpretations of the data, participants who had not registered with DSS (76 cases) were excluded from the data analysis that involved questions about DSS services. Additionally, participants who had not requested accommodations from individual instructors (58 cases) were also excluded from the data analysis concerning instructor accommodations.

Results

The most frequently reported chronic illnesses, depicted in Table 1, were chronic migraines (24.8%), asthma (18.1%), and irritable bowel syndrome (17.1%), which is similar to the general population (Beatty, 2018). General demographic information on the participants can be found in Table 2. Table 3 shows that a total of 39% of participants reported that their illness was progressive, 26.7% indicated that their illness was not progressive, and 34.3% were not sure. At the time the survey was completed, 85.7% of participants indicated that their chronic illness does follow a relapsing-remitting pattern. The length of time participants had been diagnosed with their chronic illness or illnesses varied, with 29.5% responding that they had been diagnosed for less than 1 to 3 years and 22.9% responding that they had been diagnosed for four to seven years.

This study also examined the relationship between age and whether participants believe that they are capable of completing college and holding down a job. As shown in Table 4, while the sample is skewed toward younger years, the majority agreed or strongly agreed that they have adapted to college. Somers D showed (.013; p >.05) no statistically significant relationship between age and the perception of ability to complete college and hold a job. Given the skew of the sample, it is harder to draw firm conclusions about the relationship between age and adaptation to college. Additionally, we examined the relationship between time since diagnosis and respondents’ belief that they are capable of completing college and holding a job, as shown in Table 5. The findings indicate that those who have had their diagnosis for the longest periods of time tend to agree that they have adapted the best to college and seem more likely to strongly agree (4-7 years and more than 12 years). However, Somers D indicated (-.08; p>.05) no statistically significant relationship between the number of years since diagnoses and belief in capability of completing college and holding a job.

Research Question 1

Survey results that pertain to the first research question are summarized in Table 6. This question asked how female students feel about their chronic illness in general. The vast majority of participants viewed their chronic illness as a serious condition (67.7% agreed or strongly agreed) and the vast majority also reported that their chronic illness has had a strong impact on their life (92.7%). Additionally, the results also indicate that the majority of participants have faced serious financial consequences because of their illness (68.5%). Respondents reported that their illness has had other negative effects on them as well, including depression (53.3%), anger (52.3%), fear (50.4%), and anxiety (72.4%). In terms of accepting their chronic illness, most had come to some degree of acceptance of their condition, with 68.6% of survey participants agreeing or strongly agreeing with the statement, “I accept my illness diagnosis and that it can’t be changed,” and 75.3% agreed or strongly agreed with the statement, “I am used to the idea that I have a chronic illness.” Taken together, the findings for this question suggest that most female college students living with an invisible chronic illness view and accept that their illness is a serious condition that has negatively impacted their finances and emotional well-being.

Research Question 2

Research Question 2 asked how the identity of the respondents as persons with an invisible chronic illness has been impacted by attending college. The findings in Table 7 indicate that close to a third (31.4%) of the respondents reported that they have spent a moderate or large amount of time grieving the person they were before their illness. Nearly two thirds (64.8%) of participants reported that they either agreed or strongly agreed that they often view their body as a barrier, which is known to impact one’s identity.

For the purposes of this study, identity is defined as the set of meanings associated with the self (Burke & Stets, 2000). Disability identity is defined as both an individual and social phenomenon, which is known to change based on the context of the sociocultural
Table 1

*Most Commonly Reported Types of Chronic Illness(es) of Participants*

<table>
<thead>
<tr>
<th>Type of Chronic Illness</th>
<th>N</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chronic Migraines</td>
<td>25</td>
<td>23.8</td>
</tr>
<tr>
<td>Asthma</td>
<td>19</td>
<td>18.1</td>
</tr>
<tr>
<td>IBS</td>
<td>17</td>
<td>16.2</td>
</tr>
<tr>
<td>Endometriosis</td>
<td>16</td>
<td>15.2</td>
</tr>
<tr>
<td>Fibromyalgia</td>
<td>16</td>
<td>15.2</td>
</tr>
<tr>
<td>Hashimoto's Thyroiditis</td>
<td>15</td>
<td>14.3</td>
</tr>
<tr>
<td>Arthritis</td>
<td>13</td>
<td>12.4</td>
</tr>
<tr>
<td>Chronic Fatigue Syndrome</td>
<td>10</td>
<td>9.5</td>
</tr>
<tr>
<td>Diabetes</td>
<td>8</td>
<td>7.6</td>
</tr>
<tr>
<td>Rheumatoid Arthritis</td>
<td>8</td>
<td>7.6</td>
</tr>
<tr>
<td>Ulcerative Colitis</td>
<td>7</td>
<td>6.7</td>
</tr>
<tr>
<td>Unknown Differing Diagnosis</td>
<td>7</td>
<td>6.7</td>
</tr>
<tr>
<td>Cancer</td>
<td>7</td>
<td>6.7</td>
</tr>
<tr>
<td>Mold Sensitivity</td>
<td>4</td>
<td>3.8</td>
</tr>
<tr>
<td>Crohn's</td>
<td>4</td>
<td>3.8</td>
</tr>
<tr>
<td>PCOS</td>
<td>4</td>
<td>3.8</td>
</tr>
<tr>
<td>Celiac</td>
<td>4</td>
<td>3.8</td>
</tr>
<tr>
<td>Complex Regional Pain Syndrome</td>
<td>4</td>
<td>3.8</td>
</tr>
<tr>
<td>Multiple Sclerosis</td>
<td>3</td>
<td>2.9</td>
</tr>
<tr>
<td>Hypoglycemia</td>
<td>3</td>
<td>2.9</td>
</tr>
<tr>
<td>Lyme Disease</td>
<td>3</td>
<td>2.9</td>
</tr>
</tbody>
</table>

*Note.* N=105.
Table 2

Characteristics of Participants

<table>
<thead>
<tr>
<th>Item</th>
<th>N</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age Group</td>
<td></td>
<td></td>
</tr>
<tr>
<td>17-21</td>
<td>22</td>
<td>20.9</td>
</tr>
<tr>
<td>22-26</td>
<td>34</td>
<td>32.4</td>
</tr>
<tr>
<td>27-31</td>
<td>10</td>
<td>9.5</td>
</tr>
<tr>
<td>32-36</td>
<td>14</td>
<td>13.3</td>
</tr>
<tr>
<td>37-41</td>
<td>8</td>
<td>7.6</td>
</tr>
<tr>
<td>42-51</td>
<td>10</td>
<td>9.5</td>
</tr>
<tr>
<td>52-66</td>
<td>4</td>
<td>3.8</td>
</tr>
<tr>
<td>67+</td>
<td>3</td>
<td>2.9</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>75</td>
<td>71.4</td>
</tr>
<tr>
<td>Hispanic or Latino</td>
<td>15</td>
<td>14.3</td>
</tr>
<tr>
<td>African American</td>
<td>10</td>
<td>9.5</td>
</tr>
<tr>
<td>American Indian or Alaska Native</td>
<td>4</td>
<td>3.8</td>
</tr>
<tr>
<td>Asian</td>
<td>1</td>
<td>1.0</td>
</tr>
<tr>
<td>Type of Employment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full time</td>
<td>34</td>
<td>32.4</td>
</tr>
<tr>
<td>Part time</td>
<td>39</td>
<td>37.1</td>
</tr>
<tr>
<td>Unemployed</td>
<td>32</td>
<td>30.5</td>
</tr>
<tr>
<td>Length of time as a student at this university</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1-2 semesters</td>
<td>42</td>
<td>40.0</td>
</tr>
<tr>
<td>3 semesters to 1.5 years</td>
<td>28</td>
<td>26.7</td>
</tr>
<tr>
<td>2-3.5 years</td>
<td>23</td>
<td>22.0</td>
</tr>
<tr>
<td>4-5 years</td>
<td>8</td>
<td>7.6</td>
</tr>
<tr>
<td>6+ years</td>
<td>4</td>
<td>3.8</td>
</tr>
<tr>
<td>Highest Level of Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High school or GED</td>
<td>30</td>
<td>28.6</td>
</tr>
<tr>
<td>Associates Degree</td>
<td>24</td>
<td>22.9</td>
</tr>
<tr>
<td>Bachelor’s Degree</td>
<td>36</td>
<td>34.3</td>
</tr>
<tr>
<td>Master’s Degree</td>
<td>14</td>
<td>13.3</td>
</tr>
<tr>
<td>Doctoral Degree</td>
<td>1</td>
<td>1.0</td>
</tr>
</tbody>
</table>

*Note. N=105.*
Table 3

*Information About Participants' Illness*

<table>
<thead>
<tr>
<th>Item</th>
<th>N</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Years diagnosed with illness</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1-3 years</td>
<td>31</td>
<td>29.5</td>
</tr>
<tr>
<td>4-7 years</td>
<td>24</td>
<td>22.9</td>
</tr>
<tr>
<td>8-11 years</td>
<td>19</td>
<td>18.1</td>
</tr>
<tr>
<td>12+ years</td>
<td>31</td>
<td>29.5</td>
</tr>
<tr>
<td>Is your chronic illness progressive?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>41</td>
<td>39.0</td>
</tr>
<tr>
<td>No</td>
<td>28</td>
<td>26.7</td>
</tr>
<tr>
<td>I don’t know</td>
<td>36</td>
<td>34.3</td>
</tr>
<tr>
<td>Does your illness follow a relapsing-remitting pattern?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>90</td>
<td>85.7</td>
</tr>
<tr>
<td>No</td>
<td>13</td>
<td>12.4</td>
</tr>
<tr>
<td>I don’t know</td>
<td>2</td>
<td>1.9</td>
</tr>
</tbody>
</table>

*Note. N=105.*
### Table 4

**Age and Self-Reported Level of Adaptation to College**

<table>
<thead>
<tr>
<th>Age</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Strongly Agree</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(N)</td>
<td>(%)</td>
<td>(N)</td>
<td>(%)</td>
<td>(N)</td>
<td>(%)</td>
</tr>
<tr>
<td>17-21</td>
<td>(1)</td>
<td>4.5</td>
<td>(2)</td>
<td>9.1</td>
<td>(2)</td>
<td>9.1</td>
</tr>
<tr>
<td>22-26</td>
<td>(8)</td>
<td>23.5</td>
<td>(4)</td>
<td>11.8</td>
<td>(6)</td>
<td>17.7</td>
</tr>
<tr>
<td>27-31</td>
<td>(1)</td>
<td>10.00</td>
<td>(1)</td>
<td>10.00</td>
<td>(1)</td>
<td>10.00</td>
</tr>
<tr>
<td>32-36</td>
<td>(1)</td>
<td>7.1</td>
<td>(1)</td>
<td>7.1</td>
<td>(8)</td>
<td>57.1</td>
</tr>
<tr>
<td>37-41</td>
<td>(2)</td>
<td>25.0</td>
<td>(4)</td>
<td>50.0</td>
<td>(2)</td>
<td>25.0</td>
</tr>
<tr>
<td>42-46</td>
<td>(1)</td>
<td>16.7</td>
<td>(1)</td>
<td>16.7</td>
<td>(4)</td>
<td>66.7</td>
</tr>
<tr>
<td>47-51</td>
<td>(1)</td>
<td>25.0</td>
<td>(1)</td>
<td>25.0</td>
<td>(1)</td>
<td>25.0</td>
</tr>
<tr>
<td>52-56</td>
<td>(1)</td>
<td>25.0</td>
<td>(1)</td>
<td>25.0</td>
<td>(2)</td>
<td>50.0</td>
</tr>
<tr>
<td>57-61</td>
<td></td>
<td>25.0</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>62-66</td>
<td>(1)</td>
<td>100.0</td>
<td>(1)</td>
<td>100.0</td>
<td>(3)</td>
<td>100.0</td>
</tr>
<tr>
<td>67+</td>
<td>(1)</td>
<td>33.0</td>
<td>(1)</td>
<td>33.0</td>
<td>(1)</td>
<td>33.0</td>
</tr>
</tbody>
</table>

*Note. N = 105; Somers D (-.081; p=.364).*
Table 5

Length of Time Since Diagnosis and Adaptation to College

<table>
<thead>
<tr>
<th>Years Since Diagnosis</th>
<th>Strongly Disagree (N)</th>
<th>Disagree (%)</th>
<th>Neutral (%)</th>
<th>Agree (%)</th>
<th>Strongly Agree (N)</th>
<th>Total (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-3 years</td>
<td>1(1)</td>
<td>3.2%</td>
<td>16.1%</td>
<td>29.0%</td>
<td>32.2%</td>
<td>29.5%</td>
</tr>
<tr>
<td>4-7 years</td>
<td>1(1)</td>
<td>4.16%</td>
<td>16.7%</td>
<td>20.8%</td>
<td>50.0%</td>
<td>22.9%</td>
</tr>
<tr>
<td>8-11 years</td>
<td>1(1)</td>
<td>5.3%</td>
<td>15.8%</td>
<td>47.4%</td>
<td>31.6%</td>
<td>18.0%</td>
</tr>
<tr>
<td>12 + years</td>
<td>1(1)</td>
<td>3.2%</td>
<td>16.1%</td>
<td>22.6%</td>
<td>54.8%</td>
<td>29.5%</td>
</tr>
</tbody>
</table>

Note. N=105; Somers D (.115; p=.182).
### Table 6

**How Participants Feel About Their Chronic Illness**

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Agree (N)</th>
<th>Agree (N)</th>
<th>Neutral (N)</th>
<th>Disagree (N)</th>
<th>Strongly Disagree (N)</th>
</tr>
</thead>
<tbody>
<tr>
<td>My illness is a serious condition</td>
<td>28 (26.7)</td>
<td>43 (41)</td>
<td>23 (21.9)</td>
<td>8 (7.6)</td>
<td>3 (2.9)</td>
</tr>
<tr>
<td>My illness has major consequences on my life</td>
<td>41 (39)</td>
<td>50 (47.6)</td>
<td>7 (6.7)</td>
<td>6 (5.7)</td>
<td>1 (1)</td>
</tr>
<tr>
<td>My Illness does not have much effect on my life</td>
<td>39 (3.8)</td>
<td>47.6 (3.8)</td>
<td>6.7 (42.9)</td>
<td>5.7 (49.5)</td>
<td></td>
</tr>
<tr>
<td>My illness has caused serious financial consequences</td>
<td>39 (37.1)</td>
<td>33 (12.4)</td>
<td>13 (16.2)</td>
<td>17 (16.2)</td>
<td>3 (10.5)</td>
</tr>
<tr>
<td>I get depressed when I think about my illness</td>
<td>23 (21.9)</td>
<td>33 (31.4)</td>
<td>22 (18.1)</td>
<td>19 (18.1)</td>
<td>8 (10.5)</td>
</tr>
<tr>
<td>My illness makes me feel angry</td>
<td>16 (15.2)</td>
<td>39 (37.1)</td>
<td>19 (18.1)</td>
<td>20 (19)</td>
<td>11 (10.5)</td>
</tr>
<tr>
<td>My illness makes me feel afraid</td>
<td>18 (17.1)</td>
<td>35 (33.3)</td>
<td>19 (18.1)</td>
<td>22 (21)</td>
<td>11 (10.5)</td>
</tr>
<tr>
<td>Having this illness makes me feel anxious</td>
<td>30 (28.6)</td>
<td>46 (43.8)</td>
<td>17 (16.2)</td>
<td>12 (11.4)</td>
<td>4 (3.8)</td>
</tr>
<tr>
<td>I accept my illness diagnosis and that it can't be changed</td>
<td>26 (24.8)</td>
<td>46 (43.8)</td>
<td>17 (16.2)</td>
<td>12 (11.4)</td>
<td>4 (3.8)</td>
</tr>
<tr>
<td>I am used to the idea that I have a chronic illness</td>
<td>32 (30.5)</td>
<td>47 (44.8)</td>
<td>9 (8.6)</td>
<td>15 (14.3)</td>
<td>2 (1.9)</td>
</tr>
<tr>
<td>Sometimes when I think about my illness, I say to myself ‘this isn't real’</td>
<td>5 (4.8)</td>
<td>28 (26.7)</td>
<td>10 (9.5)</td>
<td>30 (28.6)</td>
<td>32 (30.5)</td>
</tr>
<tr>
<td>There is very little that can be done to improve my illness</td>
<td>21 (20)</td>
<td>37 (35.2)</td>
<td>23 (21.9)</td>
<td>17 (16.2)</td>
<td>7 (6.7)</td>
</tr>
</tbody>
</table>

*Note. N=105.*
Table 7

*How Has College Impacted Their Identity*

<table>
<thead>
<tr>
<th></th>
<th>A lot</th>
<th>Medium Amount</th>
<th>Little bit</th>
<th>Not at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>I spend time grieving the person I was before the onset of my illness</td>
<td>(12)</td>
<td>(24)</td>
<td>(30)</td>
<td>(39)</td>
</tr>
<tr>
<td></td>
<td>11.4</td>
<td>22.9</td>
<td>28.6</td>
<td>37.1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neutral</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I often view my body as a barrier</td>
<td>(28)</td>
<td>(40)</td>
<td>(23)</td>
<td>(13)</td>
<td>(1)</td>
</tr>
<tr>
<td></td>
<td>26.7</td>
<td>38.1</td>
<td>21.9</td>
<td>12.4</td>
<td>1.0</td>
</tr>
<tr>
<td>I have felt judged by others regarding the legitimacy of my symptoms</td>
<td>(55)</td>
<td>(30)</td>
<td>(8)</td>
<td>(9)</td>
<td>(3)</td>
</tr>
<tr>
<td></td>
<td>52.4</td>
<td>28.6</td>
<td>7.6</td>
<td>8.6</td>
<td>2.9</td>
</tr>
<tr>
<td>My illness strongly affects the way others see me</td>
<td>(7)</td>
<td>(25)</td>
<td>(20)</td>
<td>(28)</td>
<td>(25)</td>
</tr>
<tr>
<td></td>
<td>6.7</td>
<td>23.8</td>
<td>19</td>
<td>26.7</td>
<td>23.8</td>
</tr>
<tr>
<td>Despite my illness, I feel just as capable as the next person of completing college and holding a job</td>
<td>(45)</td>
<td>(30)</td>
<td>(9)</td>
<td>(17)</td>
<td>(4)</td>
</tr>
<tr>
<td></td>
<td>42.9</td>
<td>28.6</td>
<td>8.6</td>
<td>16.2</td>
<td>3.8</td>
</tr>
<tr>
<td>I feel that I am a person of worth on an equal plane with others</td>
<td>(49)</td>
<td>(36)</td>
<td>(13)</td>
<td>(6)</td>
<td>(1)</td>
</tr>
<tr>
<td></td>
<td>46.7</td>
<td>34.3</td>
<td>12.4</td>
<td>5.7</td>
<td>1.0</td>
</tr>
<tr>
<td>There have been occasions when I have avoided social situations because of my illness</td>
<td>(43)</td>
<td>(51)</td>
<td>(3)</td>
<td>(8)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>41.0</td>
<td>48.6</td>
<td>2.9</td>
<td>7.6</td>
<td></td>
</tr>
<tr>
<td>Even though I have a chronic illness, it has not affected my ability to sustain close relationships</td>
<td>(23)</td>
<td>(36)</td>
<td>(10)</td>
<td>(27)</td>
<td>(9)</td>
</tr>
<tr>
<td></td>
<td>21.9</td>
<td>34.3</td>
<td>9.5</td>
<td>25.7</td>
<td>8.6</td>
</tr>
</tbody>
</table>

*Note.* N=105.
According to social identity theory, “people prefer to see themselves in a positive light, which implies that there will be a general search for positive distinctiveness in their perceptions of and dealings with other groups” (Brown, 2020, p. 5). A key finding is that 81% of respondents agreed or strongly agreed that they have felt judged by others regarding the legitimacy of the symptoms caused by their chronic illness. However, in a seeming contradiction, when asked to respond to the statement “My illness strongly affects the way others see me,” just over half (50.5%) disagreed or strongly disagreed with this statement.

The vast majority of participants (89.6%) agreed or strongly agreed that there have been occasions when they have avoided social situations because of their chronic illness. However, it is important to note that avoiding social situations on occasion because of a chronic illness does not necessarily mean that living with a chronic illness prevents one from sustaining close relationships with others. In fact, over half (56.2%) of the participants agreed or strongly agreed that their chronic illness has not affected their ability to sustain close relationships. The ability to sustain close relationships has the potential to impact one’s identity. Taken together, the findings in Table 7 suggest that having a chronic illness profoundly affects, in a number of ways, one’s identity and construction of self.

**Research Question 3**

The third research question asked how female students with an invisible chronic illness adjust to and cope with their chronic illness in the new context of college. Findings are reported in Table 8, which shows that participants reported using a number of strategies to adjust to college and to cope with their chronic illness. Only a small percentage (7.6%) reported self-medicating with drugs or alcohol as a way of coping and instead, respondents (54.3%) were much more likely to report seeking out support and someone to talk to about how they felt. The results in Table 8 also indicate that time management is an important consideration for students with a chronic illness. Almost three fourths (74.3%) of respondents agreed or strongly agreed with the statement, “I manage my time by planning ahead and prioritizing activities according to limited energy and phases of fatigue” and over half (55.2%) indicated that they either spend “quite a bit” or “a great deal” of time arranging their schedule so that they could more easily do the things they need to get done in daily life because of their illness. Taken together, the findings here suggest that the majority of the respondents living with an invisible chronic illness engage in a number of adaptive coping strategies such as time management, and seeking social support while attending college.

**Research Question 4**

Research Question 4 asked how female college students with an invisible chronic illness perceive the effectiveness of accommodations provided by individual instructors, DSS, and the university overall. Results for this question, presented in Table 9, reveal that about a quarter of respondents (24.7%) disclosed their illness to instructors only if necessary. In fact, 18.1% of survey respondents reported that they have felt they have had to disclose their chronic illness to instructors when they were not comfortable doing so. In terms of comfort with the process of disclosing to instructors, a significant percentage (43.8) reported discomfort. Over half (56.2%) of the survey respondents reported that they had not received accommodations from instructors for their chronic illness. Of the participants who have received accommodations from instructors (43.8% of the sample), 58.7% agreed or strongly agreed that the accommodations they received were appropriate, 56.5% agreed or strongly agreed that the accommodations they received were appropriate, and 77.1% of respondents indicated that they had never been denied an accommodation from an instructor.

Over two thirds (67.3%) of respondents had not registered with DSS. Of those respondents who had registered with DSS, only about 40% (41.2%) felt that the process to register with DSS at this university was easy. These respondents were also asked to evaluate how knowledgeable the DSS office was concerning chronic illnesses. Over half (52.9%) took a neutral position, neither agreeing or disagreeing, while 7.6% either agreed or strongly agreed that the DSS office is knowledgeable of chronic illness and 8.6% disagreed or strongly disagreed. Almost half of the respondents (47.1%) were neutral concerning the adequacy of their accommodations provided by DSS. Almost a third (32.3%) agreed that accommodations received from DSS were appropriate, while 10.5% either agreed or strongly agreed and 5.7% either disagreed or strongly disagreed that DSS accommodations were appropriate.

Table 9 indicates that a large majority of the participants reported feeling valued as a student at this
## Table 8

*How Participants Adjust to College and Cope with Their Illness*

<table>
<thead>
<tr>
<th></th>
<th>A lot</th>
<th>Medium</th>
<th>Little bit</th>
<th>Not at all</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(N)</td>
<td>(N)</td>
<td>(N)</td>
<td>(N)</td>
</tr>
<tr>
<td></td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td>I use alcohol or drugs to make myself feel better</td>
<td>(2)</td>
<td>(6)</td>
<td>(21)</td>
<td>(76)</td>
</tr>
<tr>
<td></td>
<td>1.9</td>
<td>5.7</td>
<td>20.0</td>
<td>72.4</td>
</tr>
<tr>
<td>I drink alcohol or take drugs in order to think about my illness less</td>
<td>(1)</td>
<td>(4)</td>
<td>(9)</td>
<td>(91)</td>
</tr>
<tr>
<td></td>
<td>1.0</td>
<td>3.8</td>
<td>8.6</td>
<td>86.7</td>
</tr>
<tr>
<td>When I need support, I talk to someone about how I feel</td>
<td>(11)</td>
<td>(46)</td>
<td>(26)</td>
<td>(22)</td>
</tr>
<tr>
<td></td>
<td>10.5</td>
<td>43.8</td>
<td>24.8</td>
<td>21.0</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>A great deal</th>
<th>Quite a bit</th>
<th>Moderate amount</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(N)</td>
<td>(N)</td>
<td>(N)</td>
<td>(N)</td>
<td>(N)</td>
</tr>
<tr>
<td></td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td>To what extent have you arranged your schedule so that you could more easily do the things you need to get done in daily life because of your illness</td>
<td>(29)</td>
<td>(29)</td>
<td>(24)</td>
<td>(18)</td>
<td>(5)</td>
</tr>
<tr>
<td></td>
<td>27.6</td>
<td>27.6</td>
<td>22.9</td>
<td>17.1</td>
<td>4.8</td>
</tr>
<tr>
<td>To what extent have you thought about or reviewed how you were doing in accomplishing your disease management goals</td>
<td>(25)</td>
<td>(26)</td>
<td>(22)</td>
<td>(27)</td>
<td>(5)</td>
</tr>
<tr>
<td></td>
<td>23.8</td>
<td>24.8</td>
<td>21.0</td>
<td>25.7</td>
<td>4.8</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>2X week</th>
<th>1X week</th>
<th>2X month</th>
<th>1X month</th>
<th>Bi-monthly</th>
</tr>
</thead>
<tbody>
<tr>
<td>I spend ____ amount of time attending doctors’ appointments related to my chronic illness</td>
<td>(2)</td>
<td>(8)</td>
<td>(18)</td>
<td>(26)</td>
<td>(51)</td>
</tr>
<tr>
<td></td>
<td>1.9</td>
<td>7.6</td>
<td>17.1</td>
<td>24.8</td>
<td>48.6</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neutral</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I try to see my illness in a positive light</td>
<td>(18)</td>
<td>(39)</td>
<td>(28)</td>
<td>(13)</td>
<td>(7)</td>
</tr>
<tr>
<td>I learn to live with my chronic illness</td>
<td>17.1</td>
<td>37.1</td>
<td>26.7</td>
<td>12.4</td>
<td>6.7</td>
</tr>
<tr>
<td>I manage my time by planning ahead and prioritizing activities according to limited energy and phases of fatigue</td>
<td>(39)</td>
<td>(55)</td>
<td>(8)</td>
<td>(2)</td>
<td>(1)</td>
</tr>
<tr>
<td></td>
<td>37.1</td>
<td>52.4</td>
<td>7.6</td>
<td>1.9</td>
<td>1.0</td>
</tr>
<tr>
<td></td>
<td>(34)</td>
<td>(44)</td>
<td>(15)</td>
<td>(6)</td>
<td>(6)</td>
</tr>
<tr>
<td></td>
<td>32.4</td>
<td>41.9</td>
<td>14.3</td>
<td>5.7</td>
<td>5.7</td>
</tr>
</tbody>
</table>

*Note. N=105.*
Table 9

*Perceived Effectiveness of Accommodations*

<table>
<thead>
<tr>
<th></th>
<th>Always</th>
<th>A lot of the time</th>
<th>Moderate amount</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>This university has rules or policies that make it easier for me to manage my illness</td>
<td>(N)</td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td>I’ve had a flexible school schedule so that I could adjust to meet my needs</td>
<td>(N)</td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td>I feel valued as a student.</td>
<td>(N)</td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td>I have felt pressured to take online courses because of my illness</td>
<td>(N)</td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td>My illness prevents me from being involved in campus activities</td>
<td>(N)</td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td>Having my illness makes it more difficult for me to make friends in college</td>
<td>(N)</td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td>I engage in efforts to hide my illness</td>
<td>(N)</td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td>The accommodations I have received from instructors have been appropriate</td>
<td>(N)</td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td>The accommodations I have received from DSS have been adequate</td>
<td>(N)</td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td>My instructors are knowledgeable of chronic illness issues and disability-support accommodations</td>
<td>(N)</td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td>The DSS office is knowledgeable on chronic illnesses.</td>
<td>(N)</td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
</tr>
</tbody>
</table>

Frequently On Occasion Twice Once Never

Have you ever been denied an accommodation from an instructor? | (N)    | %                 | %               | %        | %         |

*Note. N=105.*
university. However, nearly half (48.6%) reported that university rules or policies have not made it easier for them to manage their illness. Respondents were also asked about their ability to create a flexible school schedule that they could adjust to meet their needs. The largest single percentage (43.8%) reported that they always or a lot of the time had flexibility to do so. Over half (56.2%) of participants reported that they engage in concealment strategies.

The three most common symptoms that participants listed as posing the biggest challenge to their success at this university included fatigue (76.2%), headaches (44.5%), and gastrointestinal issues (42.9%). Over half (60%) agreed or strongly agreed that they had felt pressure to take online courses as opposed to face-to-face courses because of their chronic illness, while just over half (51.5%) reported that their illness did not negatively impact their attendance. The two most commonly listed accommodations that are the most important to their success at this university were absence accommodations (55.2%) and extended time to complete assignments (31.4%). Taken together, the findings from this question suggest that most female students who are living with an invisible chronic illness will disclose their illness to instructors only when absolutely necessary. Fatigue was reported as the symptom that poses the biggest challenge to the success of students with chronic illness. Additionally, female students living with an invisible chronic illness at this university often considered requiring medical documentation a barrier to receiving accommodations, and that their most needed accommodation was absence accommodations.

**Discussion**

It is clear that the majority of female students surveyed feel that their chronic illness is a serious condition that has profoundly impacted their life. While the majority have come to terms with accepting their illness, large numbers of respondents reported that they continue to experience significant emotional effects, including anxiety, depression, anger, and fear. This finding is consistent with other research, which has also suggested that anxiety is prevalent amongst the chronically ill population (Adams & Proctor, 2010; Livneh, Martz, & Wilson, 2001; Vickers, 2017). Nearly all of the participants indicated that they have avoided social situations because of their chronic illness. Avoiding potential stigma in social situations could partially explain this finding because the vast majority of respondents reported having felt that others often misunderstand their illness and questioned the legitimacy of their illness symptoms (Goffman, 1963). The finding of participants viewing their body as a barrier and spending a significant amount of time grieving the person they were before their illness onset indicates that having a chronic illness while attending college has the potential to profoundly impact one’s identity and construction of self. An encouraging finding was that despite their perceptions of being misunderstood and judged by others, most respondents were still able to maintain (a) a sense of themselves as capable of functioning effectively in the world and (b) positive feelings about themselves, both of which are consistent with social identity theory’s contention that “people prefer to see themselves in a positive light” (Brown, 2020, p. 5).

Coping strategies of participants revolved around time management, self-acceptance, reframing how they think about their illness, and seeking support from others. Time management was found to be important to the vast majority of participants due to fatigue and limited energy caused by their chronic illness. Significantly, over three quarters of participants listed fatigue as the symptom that poses the biggest challenge to their success at this university, which extends prior knowledge on the hidden chronic illness experience (Moore, 2012). The findings also indicate that the majority of respondents disclosed their illness to instructors only if necessary and a small percentage of respondents indicated that instructors have been unwilling to provide accommodations in the past. It was not surprising that more than any other accommodation, absence accommodations were reported by participants to be the most important to their success at this university. This might also partially explain the finding that around 60% of the survey participants reported that they have felt pressured to take online courses due to their illness.

This study is consistent with previous research that finds that requiring medical documentation of a disability is a barrier to receiving accommodations (Riddell & Weedon, 2014); almost a quarter of participants listed medical documentation as a barrier that they have experienced to receiving accommodations. Most students did not perceive being negatively judged by their peers for absences or lack of participation, however almost a quarter indicated that they had perceived negative judgement from their instructors due to their chronic illness. A new finding that should not be taken lightly was that students with a hidden chronic illness have actually received entire letter reductions in their grades due to compulsory attendance policies.
Implications

The findings in this study suggest the need for universities to review their policies that disadvantage students with hidden chronic illnesses. Universities should take into consideration how policies disadvantage students with invisible illnesses by using the British Social Model of Disability, which can help shed light on the struggles faced by students living with an invisible chronic illness. According to this model, when social structures, such as university departments and offices, fail to properly accommodate individuals with hidden chronic illnesses, they further contribute to oppressing and disadvantaging this population (Clark, 2006; Evans, 2017). The findings in this study suggest that public universities should focus not only on ADA compliance, but also on inclusion of all marginalized students, which includes students with hidden illness.

The data in this study imply that higher education needs to find ways to encourage disclosure among students and faculty. Students with chronic illnesses may perceive that disclosure may be stigmatizing and would not necessarily lead to improved outcomes for them. The situation with disclosure may be complicated by gender specific issues such as aspects of traditional gender role socialization that may discourage women from stepping forward and disclosing their illness. In addition, racial or ethnic issues may impact the willingness and comfort of female students in disclosing their disability status.

The findings suggest a continued need for theory development that effectively develops and elaborates a more detailed understanding of the experiences of college females who are coping with a potentially stigmatizing chronic illness while also navigating the experience of higher education in an institutional setting that may lack the flexibility to effectively accommodate their needs. Additionally, a more fully developed theoretical understanding should incorporate an understanding of the intersectional effects of race, ethnicity, and gender.

Encouraging disclosure means raising disability awareness and fostering positive attitudes towards disability. Fostering an environment that provides students with invisible chronic illnesses to meet other students in similar situations can provide “a sense of validation of your physical condition, of your emotional feelings and perhaps some relief from isolation” (Moore, 2012, p. 206). Instructors can provide better accommodations to students when they are aware of a student’s hidden impairments; thus, our findings suggest that educational institutions need to find ways to foster an environment that encourages students to disclose their hidden impairments (Matthews, 2009). Disability services offices can play a role in fostering greater faculty awareness of disability issues so that faculty are better informed and can therefore be more easily enlisted as advocates for students with hidden disabilities in need of accommodations.

A number of colleges and universities have programs in place that may be helpful for disability offices to consider implementing. Marist College in Poughkeepsie, New York has a specific program in their disability support office that helps to prepare students to discuss their accommodation needs with professors (Understood For All Inc, 2020). The University of Michigan’s disability support office created “Campus Mind Works,” which is an online resource where students who are diagnosed with an ongoing mental health disorder can get information about managing their illness as well as how to get the most out of their college experience (University of Michigan, 2020). Additionally, the University of Michigan’s disability support office has a separate and specific registration process for students with chronic health conditions.

The findings in this study suggest that university policies regarding absences should be examined and revised when it is determined that these policies may be disadvantaging students with hidden chronic illness. The finding that a small percentage of participants have experienced reductions in their grades as a result of missing class due to their chronic illness should not be taken lightly. This finding was compounded by the fact that more than any other accommodation, absence accommodations were reported by participants to be the most important to their success as students. The findings in this study suggest that it may be challenging for students with hidden chronic illnesses to succeed in environments that implement compulsory attendance policies. Colleges and universities should review and revise policies of this nature that are a hindrance to students with hidden chronic illness. Additionally, the finding that over a quarter of participants listed medical documentation as a barrier to receiving accommodations means that this needs to be addressed by DSS offices as well.

Limitations and Future Research

It is crucial that future research continues to further explore obstacles and barriers faced by female college students who are living with an invisible chronic illness. Future research should also continue to examine how this population adjusts and copes with their illness, and propose potential policy solutions within colleges and universities.

Because African American women comprised only 9.5% of this study’s sample, this study does
not capture the chronic illness experience of African American women attending college. The heterogeneity of the factors mentioned above in this sample washes out between group differences, which can cause us to overlook important aspects of different individuals’ experiences. For example, given that African American women are affected by Lupus at higher rates than any other female ethnic group, research regarding the chronic illness experience of African American college women is needed and necessary (Rosales & Person, 2003).

Additionally, because quantitative studies often fail to fully capture true depictions of the invisible chronic illness experience, authentic narratives of those living with invisible chronic illness while attending college are crucial to a complete understanding of such lived experiences (Moore, 2012). Detached, removed third parties have conducted most of the current research on this topic, which highlights the need for more research in this area to use an auto-ethnographic process to better capture the chronic illness experience (Green et al., 2005; Moore, 2012; Pena, 2014). Additionally, a participatory action approach may be helpful to researchers. Due to all participants being from the same geographical location, results cannot be generalized to all female college students living with a hidden chronic illness. Another limitation of this study is that the survey relied on the honesty and accuracy of the participants’ responses.

The finding that 60% of the survey participants reported that they have felt pressured to take online courses due to their illness warrants further investigation. As noted, a significant percentage of the respondents reported that they had not registered with DSS. One possible reason for this finding is that students may not realize that they qualify for accommodations through DSS because of their chronic illness. Another possibility is that students are fearful of discrimination and potential stigma that comes with registering with DSS, as this study revealed that fear of discrimination and stigma was prevalent among respondents who were living with an invisible illness. The finding that 81% of the participants either agreed or strongly agreed that they have felt judged by others regarding the legitimacy of their illness symptoms, as well as the fact that over half of the participants engage in “concealment strategies” (Goffman, 1963, p. 87), reaffirms that living with an invisible illness is often extremely stigmatizing.

The majority of respondents reported having felt that others often misunderstand their illness, question the legitimacy of their illness symptoms, that they have avoided social situations because of their illness. They often view their body as a barrier, and they spend a significant amount of time grieving the person they were before their illness onset, all of which indicate that having a chronic illness while attending college has the potential to profoundly impact one’s sense of identity and construction of self. At the same time, a reassuring finding in this study reveals that in spite of the struggles faced by respondents, most were still able to maintain a sense of themselves as capable of functioning effectively in the world with positive feelings about themselves as well as utilize healthy coping skills.

Additional research is warranted to investigate how the identity of a person with a chronic illness changes and adjusts throughout the life experience. Constantly fluctuating and progressing symptoms of chronic illness require continual adjustments on behalf of the person, which means that the process of adjustment will be ongoing and changing (Bury, 1982; Mintz, 2007). Disruptions in the everyday taken-for-granted assumptions in the individual’s plans for the future that so often characterize chronic illness cast a shadow of anxiety and uncertainty for the college student living with an invisible illness (Riddell & Weendon, 2014). Understanding how invisible chronic illness impacts the lives of female college students should be important to universities because this population is increasing, but it should also be important to scholars because much can be learned about day-to-day situations by analyzing situations and circumstances that are “radically disturbed” (Bury, 1982, p. 169; Moore, 2012).

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### About the Authors

Danielle Barber received her M.A. degree in sociology from Texas Woman’s University and is a current Ph.D. candidate at Texas Woman’s University. Her experience includes working as a graduate teaching assistant for Texas Woman’s University in the department of Sociology. Her research interests include sociology of disabilities and sociology of health and illness. She can be reached by email at: dbarbr2@twu.edu.

James L. Williams is Professor of Sociology and Graduate Program Director at Texas Woman’s University. He received his Ph.D. from the University of Georgia. His research and teaching interests include Criminology, Social Psychology, and Global and Transnational Sociology. Recent publications include studies of collective action in a college classroom setting, dimensions of religion and attitudes toward euthanasia, and juvenile delinquency in Turkey. He can be reached by email at: jwilliams2@twu.edu.
Students with Anxiety Disorders: Self-Advocacy, Daily Life Activities, and Meaningfulness of the College Experience

Amy Hasman¹
Cynthia Matlock¹

Abstract

Students with disabilities are attending college in increasing numbers (Kim & Lee, 2016); consequently, academic, disability, and counseling resources directed toward full participation in the college experience are strained. To access support resources, college students must assume the responsibility of disclosing their disability and seek assistance without help from parents or teachers (Evans et al., 2017; McCarthy, 2007). Seeking assistance requires knowledge of resources and effective communication skills. Communication, especially the ability to advocate for self, is an essential, yet often a challenging skill for the student with a disability (Daly-Cano et al., 2015). Self-advocacy requires conveying needs and wants to achieve academic success and engagement in the college environment (Stodden et al., 2003). The purpose of this qualitative phenomenological descriptive inquiry was twofold: to understand how college students with an anxiety disorder perceive self-advocacy and second, to understand how self-advocacy influences their daily life activities related to the college experience. The results revealed that although self-advocacy was difficult to learn and master, students recognized the value of self-advocating. As students learned to self-advocate, they experienced more success responding to challenges. Further, students identified the most daunting daily life activities to navigate within the college environment as health management, education participation, communication management, social participation, and sleep participation. Study participants included a criterion purposive sampling of 10 college students. Eight students identified as female and two identified as male. The students ranged in age from 19-31 years old. They were diagnosed with an anxiety disorder, had disclosed their disability, and were registered with disability services.

Keywords: self-advocacy, anxiety, college student, daily life activities, students with disabilities

As students transition to college, they experience challenges including unfamiliar academic workloads, new daily life activities and personal responsibilities, and changing relationships (Traino et al., 2019). The transition for students with mental health disabilities may be even more concerning as they struggle to self-advocate for their academic rights (Kreider et al., 2015). According to the National Center on Education Statistics (NCES) and the National Council on Disability (NCD), the number of students with physical and mental health disabilities enrolling in college with the desire to obtain a degree continues to increase (Kim & Lee, 2016). National data reflect that approximately 19% of college students report having a disability (The Postsecondary National Policy Institute, 2018). Regarding a mental health diagnosis, onset typically occurs prior to age 25 (Alonso et al., 2018; Hartrey et al., 2017; Schindler & Kientz, 2013) when some individuals are attending college and away from traditional support systems (Hartrey et al., 2017). Parent and teacher support, in the form of advocacy, is expected in elementary and secondary education, but in college, advocacy is the student’s responsibility (Evans et al., 2017; McCarthy, 2007). The influential elements of self-advocacy aligned with this study include understanding oneself and one’s rights, being able to communicate with others, and taking initiative (Daly-Cano et al., 2015). Lacking experiences to self-advocate, many students are simply unprepared to do so. Because students are unprepared to self-advocate, they often do not know where to turn for help on a college campus, thus impacting many aspects of their college experience (Hong, 2015; Johnson & Irving, 2008).

¹ Saint Louis University
Standard support for students with mental health disabilities on a college campus includes obtaining accommodations through disability services, seeking clinical management through a university or college counseling center, or a combination of both. Often, accommodations primarily focus on learning and academics, and the students’ daily life activities are disregarded (Myers et al., 2013). This narrow focus can result in obstacles to full participation in campus life for the student with a mental health disability (Robbins et al., 2018). Overcoming these obstacles requires some degree of self-advocacy.

Self-advocacy is an important skill for individuals as they approach adulthood (Roberts et al., 2016). Understanding and advocating for disability rights are significant for the college student with a mental health disability as they navigate accommodations and daily life activities within the college environment. Focusing on students with anxiety disorders, this inquiry sought to understand perceptions of self-advocacy for the college student with an anxiety disorder, and to understand how self-advocacy influences daily life activities.

Literature Review

Disability Law and Mental Health

Disability law addresses the civil and legal rights of individuals with disabilities. These rights safeguard against discrimination in employment, housing, access to public services, and education. Passed in 1990, the Americans with Disabilities Act (ADA) is an all-inclusive act that ensures individuals with disabilities have the same opportunities as Americans without disabilities (U.S. Department of Justice Civil Rights Division, n.d.). A second essential act is the Rehabilitation Act of 1973. This Act states that a qualified individual with a disability shall not be excluded from programs receiving federal financial assistance, which includes colleges and universities (29 U.S.C. § 701). Thus, students with documented disabilities have both a civil and legal right to access education. Disability status is fluid and may vary in duration and timing, affect a variety of systems within the body, be stable, episodic, chronic or temporary and affect most people at some time in their lives (Evans et al., 2017). Compliance with disability law includes providing accommodations that facilitate learning or participation.

Recent data trends reveal the continual increase of college students with diagnosed mental health disabilities (Lipson et al., 2019). Three of five students report experiencing the feeling of “overwhelming anxiety” (Roy, 2018, p. 10). Although anxiety is common for college students, it may be considered an anxiety disorder when experienced consistently (American Psychiatric Association, 2013). Anxiety involves emotions of worry and fear which may be an irrational response to a particular event (American Psychiatric Association, 2013). Anxiety disorders commonly disrupt student roles (Alonso et al., 2018) and affect identity perceptions (Vaccaro et al., 2015). Students with disabilities experience fluctuations in self-perceptions of identity through their interactions with others in the classroom and on campus. Thus, when a student’s identity is impacted, participation in daily life activities, education, health management, and social activities becomes challenging (Kreider et al., 2015).

Student Identity and Accommodations

Higher education institutions must comply with disability law. It is essential that students with disabilities understand their legal rights in education. Navigating the college experience requires having the ability to seek and advocate for resources, resulting in accommodations for identified and approved needs. Many students, however, have limited knowledge of the process and may even forgo accommodations (Kreider et al., 2015; Prince, 2015) due to:

- lack of self-advocacy skills (Hong, 2015)
- stigma, attitudes of unfairness, and cynicism from professors and peers as accommodations are used (Kreider et al., 2015)
- discrimination or fear of being treated differently from “normal” peers, being viewed as incapable of completing the coursework (Hong, 2015)
- social isolation from peers or being labeled as a “disabled person” when using accommodations (Hong, 2015, p. 220)
- lack of awareness of how to access or navigate disability services (Hong, 2015)
- desire for a sense of belonging (Vaccaro et al., 2015)
- desire for success without assistance (Kreider et al., 2015)

When students do not have adequate self-advocacy skills and choose not to pursue accommodations, academic performance and daily life activities become challenging (Fleming et al., 2018; Kreider et al., 2015).

Daily Life Activities/Occupations

Daily life activities, also referred to as “occupations,” within the methods and procedures of this
study include nine categories: activities of daily living (ADLs), instrumental activities of daily living (IADLs), health management, rest and sleep, education, work, play, leisure, and social participation (American Occupational Therapy Association, 2014). Expanding on the definition of daily life activities, they are “central to a person’s health, identity, and sense of competence and have particular meaning and value to that client” (p. S7). Some common examples of occupations for the college student include laundering clothes, cleaning their living space in a residence hall, accessing food sources on campus or grocery shopping, managing their time, managing their money, attending classes, seeking health care, or joining an organization. In brief, daily life activities include “things people need to, want to and are expected to do” (World Federation of Occupational Therapists, 2012, para. 2).

These daily life activities contribute to a well-balanced and fully functional lifestyle. Students with disabilities are particularly vulnerable to disrupted daily life activities within the college environment (Schindler, 2019) and may encounter challenges when struggling with adequate self-advocacy skills (McCarthy, 2007). Conversely, accommodating academic, domestic, and social aspects can result in a meaningful college experience (Spencer et al., 2018). When students with a mental health disability understand disability rights, issues of identity, the accommodation process, participation in daily life activities, and the significance of self-advocacy skills, they are better able to facilitate a meaningful college experience.

**Statement of Significance**

In terms of seeking accommodations in college, parents and teachers, as discussed above, are no longer responsible for advocating on behalf of students (Evans et al., 2017; McCarthy, 2007). Instead, students who decide to seek accommodations must disclose their disabilities to a disability service professional on campus (Hsiao et al., 2018). According to McCarthy, (2007) “for students with disabilities, self-advocacy is not preferred; it is essential” (p. 16). However, for many students, self-disclosure and self-advocacy present barriers (Hong, 2015; Kreider et al., 2015). Many students with mental health disabilities, in particular, struggle with self-advocacy when attempting to secure their academic rights (Kreider et al., 2015).

In addition to requiring academic support in the form of accommodations, students with mental health disabilities struggle with their identities as individuals with a disability, and struggle with how to navigate their daily life activities within the new college environment. Campus life involves an intricate interplay of personal and environmental factors which influence daily life activities (Lahav et al., 2016). These factors extend beyond the classroom, contributing to identity and belonging in the college environment which is especially important for college students with disabilities (Vaccaro et al., 2015).

Students have access to campus services such as the disability service office or counseling center, but both require the student to initiate and self-advocate (Evans et al., 2017; McCarthy, 2007). Even if the student is able to self-advocate, and request services, disability service professionals and campus counselors are often overwhelmed as the number of individuals seeking services increases yearly (Prince, 2015; Wesley, 2019). Research indicates that universities must provide more thorough support to students with mental health disabilities (Francis et al., 2018). According to Myers et al. (2013), “An institution’s mission should not only be to follow the letter of the law but also to embrace and demonstrate the spirit of the law through how students are treated on a daily basis” (p. 31). Colleges and universities need additional programming and services to support these students (Evans et al., 2017) beyond what the law requires. Many studies discuss self-advocacy skills for college students with disabilities, however, there is a gap in addressing how self-advocacy impacts daily life activities for college students with anxiety disorders.

**Project Description**

**Study Background**

The researcher, an occupational therapist, utilized the Ecology of Human Performance (EHP) framework, which is a guiding framework within the occupational therapy profession that takes a holistic perspective and interdisciplinary approach. EHP considers the person, context, task, and performance. In this study, students (the person) are interconnected with their contexts which include age, developmental stage, life cycle, health status, and the physical, social, and cultural aspects of their environments (Dunn et al., 1994; Dunn et al., 2003). The framework assimilates a phenomenological and physical perspective when analyzing the person and context relationship (Dunn et al., 1994). Tasks are behaviors that allow an individual to achieve person-centered goals, which additionally contribute to their roles and daily life activities/occupations (Dunn et al., 2003). Finally, performance is the student’s ability “to engage in tasks” within their preferred context (p. 227).

This framework supports an interdisciplinary approach (Dunn et al., 2003), which is important...
as we attempt to address the needs of students with mental health disabilities in higher education and create a team of allies to provide additional support. This study focused on exploring the perceptions of self-advocacy for students with anxiety disorders as related to their participation in meaningful daily life activities/occupations associated with their college experience.

• The primary research question was: What are the perceptions of self-advocacy for college students with anxiety disorders?
• The second research question was: How does self-advocacy impact occupational engagement as related to the student's college experience?

Methods and Procedures

Study Design

The researcher chose a qualitative phenomenological approach to uncover exploratory and descriptive knowledge (Crookes & Davies, 2004) and to understand the essence of each student’s lived experience, including what and how they experience the phenomenon (Creswell, 2013; Crookes & Davies, 2004; Cypress, 2018). EHP, the theoretical framework, supports this comprehensive perspective by providing a holistic view of the person, context, task, and performance of each student (Dunn et al., 2003). Study participants, higher education students with anxiety disorders, chose to participate based on criterion sampling. All students who participated completed a Research Study Consent Form. The university’s institutional review board approved the IRB protocol.

Recruitment Strategy and Participants

The university director of disability services contacted 156 students with documented and disclosed anxiety disorders. All students received an electronic mailing which included a brief message introducing the study with an attached recruitment letter. Student information was not shared with the researcher or other potential participants. Minors or those who had not disclosed an anxiety disorder to disability services were the only individuals excluded from this study. The researcher did not have contact with any students until after they read the recruitment materials and chose to contact the researcher. Of the 156 students who received the study recruitment materials, 12 contacted the researcher via email or text message and 10 of those chose to participate. The study cohort consisted of eight participants who identified as female and two participants who identified as male. The age range was 19-31 years old.

Data Collection

Prior to beginning each interview, per phenomenological suggestion, the researcher shared the motivation for this study with the students (Creswell, 2013). They completed a consent form, a HIPAA form, and were given the opportunity to ask any questions pertaining to the nature of the study. The researcher completed individual meetings in private office space and audio recorded interviews to ensure fidelity upon transcription. Each interview lasted approximately 90 minutes.

The two data collection strategies included semi-structured, open-ended interview questions pertaining to student perceptions of self-advocacy and the Occupational Profile Template. An explanation of each strategy follows.

Self-Advocacy Questions. The researcher independently developed the open-ended questions for this study based on common themes and concepts pertaining to self-advocacy cited in referenced literature. A panel of doctoral educated professionals reviewed the questions including the director of disability services and two faculty in the occupational science/occupational therapy department (see Table 1).

The Occupational Profile Template. An occupational therapist possesses unique expertise in daily life activities (occupations) and, therefore, may use the Occupational Profile Template as a tool for better understanding the student’s viewpoint and history (American Occupational Therapy Association, 2017). The Occupational Profile Template is a tool to help determine the student’s priorities, goals, and interests, which in turn helps the student identify meaningful daily life activities that can be impacted by self-advocacy skills. The researcher modified the first question of the occupational profile to make it more pertinent for the study participants. Page numbers listed on the Occupational Profile Template correlate to the definitions in the Occupational Therapy Practice Framework: Domain and Process, 3rd Edition (OTPF) (American Occupational Therapy Association, 2014). According to the OTPF, occupation is considered the “daily life activities in which people engage;” the framework identifies an extensive list of these daily life activities (p. S6). All students were provided definitions from the OTPF to promote consistency among responses.

Analysis

The researcher audio-recorded each participant interview, transcribed all questions, and to assure accuracy, performed a second review of each interview and transcription. In phenomenological research, the researcher expects the phenomenon to emerge with-
out predetermined expectations (Cypress, 2018). The researcher used open coding to highlight recurring or distinct themes and identify significant participant quotes to aid in explanation of the theme. From each data set, the researcher drew conclusions about the students’ perceptions of self-advocacy and how it influences their engagement with the college experience. The researcher assigned participants an ID number and pseudonym to ensure anonymity and reduce identifiers and coded audio recordings and transcripts with an ID number linked to participant names and contact numbers. Audio recordings were transcribed and uploaded to a secure server with password protection. The researcher kept coded transcripts, data, and the master key separate from contact information in a locked cabinet in the Occupational Science/Occupational Therapy department.

Findings

The researcher organized the outcomes of this study into two categories based on data collection strategies. Initial findings include the themes that developed from semi-structured self-advocacy questions (see Table 2). Next, the researcher uncovered five distinct daily life activities based on the Occupational Profile Template (see Table 3).

Outcomes

Self-Advocacy Questions

All participants answered semi-structured interview questions pertaining to self-advocacy to address the first research question: What are the perceptions of self-advocacy for students with anxiety disorders in higher education? The themes that emerged included interpretations of self-advocacy, associated feelings with self-advocacy and anxiety, the value of self-advocacy, personal experiences, and the journey toward self-advocacy (see Figure 1).

Interpretation

First, it was essential for the researcher to discern each student’s interpretation of self-advocacy. Each student’s life story included understanding, articulating, and practicing self-advocacy to varying degrees, and students explained different self-advocacy definitions during the interview process. Students defined self-advocacy as speaking up and/or standing up for oneself, taking initiative and action, and getting what one needs. Self-advocating is also a way to acknowledge one’s weaknesses and share what is unique to that individual. One student named Lucy defined self-advocacy as “working so that you have a voice and your needs are met.” The age of onset and diagnosis varied for each student; therefore, self-advocacy materialized during different stages. For example, a student named Kate discussed how she learned to self-advocate in college, whereas some students were still learning.

Feelings

All participants sufficiently articulated the meaning of self-advocacy; however, feelings about self-advocacy differed. Two students revealed positive feelings linked to self-advocating as Kenneth stated, “it feels ok.” Erin was currently confident about self-advocating, but in the past, she kept to herself and did not self-advocate. According to Erin, a lack of self-advocacy “hurt me in the long run.” To accomplish preferred tasks and goals, Erin learned that self-advocacy was an essential skill. Most students associated negative feelings with self-advocating, including feeling anxious, scared, uncertain, embarrassed, frustrated, disrespected, and angry. Anger and disrespect loomed when students felt wrongfully challenged about their anxiety disorder and/or their academic accommodations. For example, in reference to accommodations, Kelly said, “I went through a lot to get this and it is really disrespectful and inappropriate for you to challenge me even though I’m your student or I am young.” Kelly expressed strong feelings associated with perceptions surrounding her accommodations.

Not only does the thought of self-advocating generate both positive and negative feelings, but the student must navigate and manage the symptoms of anxiety as well. Anxiety manifested both physically and emotionally for the students interviewed. Physical symptoms included stomach pain, fatigue, feeling like nerves are exposed, shortness of breath, and increased heart rate. When discussing anxiety symptoms, Kelly stated, “It just kind of seeps out of me in every way that it can.” The symptoms of anxiety can be so debilitating that students have difficulty getting out of bed to attend class or take an exam. In terms of emotional symptoms, Henry reported that he does “not feel mentally present” when experiencing anxiety. Kate is impacted socially when her anxiety is heightened and stated, “I might be more difficult to hang around because I’m in my own head.” Thoughts of failure tended to consume her.

Value

As indicated in the interviews, most students associated negative feelings with the thought of self-advocating. Despite the overwhelming negativity, all students believed self-advocacy to be an important and essential skill to their development and success.
Table 1

**Supporting Literature for Self-Advocacy Questions**

<table>
<thead>
<tr>
<th>Self-Advocacy question developed based on supporting literature</th>
<th>Supporting Literature – guiding the development of self-advocacy questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>What does the term self-advocacy mean to you?</td>
<td>Understanding one’s rights, communicating with others, and taking initiative, (Daly-Cano et al., 2015).</td>
</tr>
<tr>
<td>How do you feel when you know you need to advocate for yourself (self-advocate) within the college environment?</td>
<td>Mental/Emotional Struggles, (Hong, 2015).</td>
</tr>
<tr>
<td>How do you experience your anxiety?</td>
<td>Self-advocacy improves college experience, (Vaccaro et al., 2015).</td>
</tr>
<tr>
<td>When thinking about your anxiety disorder, talk about why self-advocacy may or may not be important.</td>
<td>Self- advocacy is essential, (McCarthy, 2007).</td>
</tr>
<tr>
<td>During your lifetime, describe a situation in which you needed to self-advocate.</td>
<td>Importance of self-advocacy, (Daly-Cano et al., 2015).</td>
</tr>
<tr>
<td>When requesting or discussing accommodations, describe your interactions with individuals you classify as authority figures.</td>
<td>Faculty Perceptions, (Hong, 2015).</td>
</tr>
<tr>
<td>If you have spoken to your peers about your accommodations, describe your interactions with them once they know you are receiving accommodations.</td>
<td>Learning to self-advocate, (Daly-Cano et al., 2015).</td>
</tr>
<tr>
<td>Describe your support systems prior to entering college.</td>
<td>Navigating the college experience, (Kreider et al., 2015).</td>
</tr>
<tr>
<td>Describe your support systems as a college student.</td>
<td>Experiences with faculty, staff, and peers, (Evans et al., 2017).</td>
</tr>
<tr>
<td>As a college student, how do you educate others about your anxiety disorder?</td>
<td>Quality of Support Services, (Hong, 2015).</td>
</tr>
<tr>
<td></td>
<td>Family Support, (Francis et al., 2018).</td>
</tr>
<tr>
<td></td>
<td>Supportive relationships and belonging, (Vaccaro et al., 2015).</td>
</tr>
<tr>
<td></td>
<td>Advocacy is a journey, (McCarthy, 2007).</td>
</tr>
<tr>
<td></td>
<td>Family support, (Daly-Cano et al., 2015).</td>
</tr>
</tbody>
</table>

*Note.* The researcher developed self-advocacy questions based on common and reoccurring themes in recent literature as noted in Table 1.
### Table 2

*Process of Identifying Themes for Self-Advocacy Questions*

<table>
<thead>
<tr>
<th>Self-Advocacy question from which theme was derived</th>
<th>Significant Participant quotes which illustrate the definition and theme</th>
<th>Emerging themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>What does the term self-advocacy mean to you?</td>
<td>“Working to have representation or understanding of whatever you are going through. Working so that you have a voice and your needs are met.” (4)</td>
<td>Interpretation</td>
</tr>
<tr>
<td>How do you feel when you need to advocate for yourself (self-advocate) within the college environment?</td>
<td>“If I need to self-advocate because someone is not believing me or following my accommodations, that makes me angry because they were so hard to get.” (1)</td>
<td>Feelings</td>
</tr>
<tr>
<td>How do you experience your anxiety?</td>
<td>“Anxious. Very anxious and frustrated a lot. I know I need to do it, but it is still hard. I don’t know how people are going to think of me or how they are going to react or if I’ll even accomplish anything.” (8)</td>
<td></td>
</tr>
<tr>
<td>When thinking about your anxiety disorder, talk about why self-advocacy may or may not be important.</td>
<td>“If you don’t advocate for yourself, you're not going to heal and if you don’t advocate for yourself, you may not even believe that you need help.” (10)</td>
<td>Value</td>
</tr>
<tr>
<td>During your lifetime, describe a situation in which you needed to self-advocate.</td>
<td>“Talking with teachers and doctors and explaining what I need.” (1)</td>
<td>Personal Experiences</td>
</tr>
<tr>
<td>When requesting or discussing accommodations, describe your interactions with individuals you classify as authority figures.</td>
<td>“Advocating for yourself to yourself.” (10)</td>
<td></td>
</tr>
<tr>
<td>If you have spoken to your peers about your accommodations, describe your interactions with them once they know you are receiving accommodations.</td>
<td>“To be a self-advocate is hard if you don’t have a lot of support from other people. The reason I was able to be a self-advocate is that I felt supported by most of my peers, mom, and psychologist. Without that support, I don’t know if I would be as vocal or feel as confident.” (9)</td>
<td>Journey Guided by Support</td>
</tr>
<tr>
<td>Describe your support systems prior to entering college.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Describe your support systems as a college student.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>As a college student, how do you educate others about your anxiety disorder?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Note.* The researcher derived self-advocacy themes from participant answers to the self-advocacy questions. The number after each significant participant quote correlates to the assigned participant number in Table 4.
# Table 3

**Challenging Daily Life Activities for Students with Anxiety Disorders as Impacted by Self-Advocacy**

<table>
<thead>
<tr>
<th>Foundational Themes as Identified in <em>Occupational Therapy Practice Framework, 3rd Edition</em></th>
<th>Definition from <em>Occupational Therapy Practice Framework, 3rd Edition</em></th>
<th>Significant Participant quotes which best illustrate the definition and theme</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Health Management</strong>&lt;sup&gt;1&lt;/sup&gt;</td>
<td>Health Management and Maintenance:&lt;p&gt;“Developing, managing, and maintaining routines for health and wellness promotion, such as physical fitness, nutrition, decreased health risk behaviors, and medication routines” (OTPF, 2014, p. S19).&lt;p&gt;</td>
<td>“It’s a complicated process getting diagnosis overall.” “It took a while to get to a good point.” (7) “It’s hard to find the right medications and dose.” (3)</td>
</tr>
<tr>
<td><strong>Education Participation</strong></td>
<td>Formal Education Participation:&lt;p&gt;“Participating in academic, nonacademic, and vocational educational activities” (OTPF, 2014, p. S20).&lt;p&gt;</td>
<td>“Under normal circumstances, I’m pretty productive, but once I get to the point where I’m so overwhelmed, I can’t do anything, and I don’t know where to start.” (8)</td>
</tr>
<tr>
<td><strong>Social Participation</strong></td>
<td>Social Participation:&lt;p&gt;“The interweaving of occupations to support desired engagement in community and family activities as well as those involving peers and friends; involvement in a subset of activities that involve social situations with others and that support social interdependence” (OTPF, 2014, p. S21).&lt;p&gt;</td>
<td>“Being so concerned about what others think of me hinders a lot and dictates a lot of what I do.” (8) “Social is always an issue.” “Junior year - really aching for social experiences.” (5)</td>
</tr>
<tr>
<td><strong>Sleep Participation</strong></td>
<td>Sleep Preparation &amp; Sleep Participation:&lt;p&gt;“Engaging in routines that prepare the self for a comfortable rest…Preparing the physical environment for periods of unconsciousness…”&lt;p&gt;“Taking care of personal needs for sleep, such as ceasing activities to ensure onset of sleep, napping, and dreaming; sustaining a sleep state without disruption; and performing nighttime care…” (OTPF, 2014, p. S20).&lt;p&gt;</td>
<td>“Sometimes I have a hard time falling asleep and I usually can’t stay asleep.” “I have had a lot of issues with sleep in my life.” (1)</td>
</tr>
</tbody>
</table>
(Table 3 Continued)

Communication Management: “Sending, receiving, and interpreting information using a variety of systems and equipment, including writing tools, telephones, keyboards, audiovisual recorders, computers or tablets, communication boards, call lights, emergency systems, Braille writers, telecommunication devices for deaf people, augmentative communication systems, and personal digital assistants” (OTPF, 2014, p. S19).

“I feel like social media is not productive unless I’m using it to learn more or laugh at.” “I don’t like scrolling and looking at what people are doing. I feel like that makes me feel worse about myself.” (10)

Note. Conducting the Occupational Profile Template and providing participants with definitions from the OTPF (AOTA, 2014) led to these five themes. The five daily life activities/occupations listed in Table 3 were impacted by self-advocacy and were the most challenging for students in this study.

Figure 1

Conceptual Diagram Illustrating the Themes Pertaining to the Students’ Perceptions of Self-Advocacy

Note. At the core is the first research question, “what are the perceptions of self-advocacy for students with anxiety disorders?”
Students recognized the value of self-advocating as one described self-advocacy as a way to promote growth and healing. While they perceived the value, students reiterated that it was difficult to self-advocate and that self-advocacy is a learned skill. Carrie stated, “It is so hard to advocate for yourself as someone with anxiety because it is so anxiety provoking.” Yet, students learned that anxiety increases if they do not advocate for themselves. It is important to consider that anxiety is an invisible disability that makes self-advocacy imperative. According to Kelly, “If you don’t speak up about it, no one is going to know it is there or that it exists.” Due to the nature of this invisible disability, students struggled with others understanding or believing their needs.

Personal Experiences

Each student shared personal experiences of having to self-advocate in the college environment. Initial experiences included disclosing feelings, concerns, or disabilities to teachers, doctors, and disability service professionals. These early experiences were often a critical juncture in understanding one’s needs. As students obtained diagnoses and began to figure out their disability, they were able to begin educating others and eventually self-advocate. According to Kate, “Going to disability services and saying something was wrong was self-advocacy.” Kelly discussed how she talked with her teachers about her needs and didn’t mind explaining her necessary accommodations. Other students had mixed feelings about the student-professor relationship. Some trusted professors and were willing to engage in disability related conversations while others felt it was unnecessary for professors to understand the disability or why they needed accommodations. Tara stated, “It’s not my obligation to explain my disorders to other people. The people that already need to know about it, know about it.” Likewise, Rachel did not openly discuss her needs, but said, “Sometimes I do wish I could talk about it so people could understand why I do or don’t do certain things.”

Students were more guarded and selective when deciding with which peers to share their disability related experiences. Kelly stated, “I never tell people if I don’t feel comfortable. I would never do that to myself.” She was cautious when determining whom she could trust. According to Kelly, “With peers, I never come right out and say it if I don’t feel a need to.” Students often had a select group of friends to whom they felt safe disclosing, but did not openly discuss their disability with a larger population.

Journey Guided by Support

Students were at different places in their self-advocacy journeys and required a great deal of support from others. Without support, most students felt they would not find success with the college experience. All students reported using parents as significant support systems with the mother being relied on the most. According to Kate, “Mom has still remained a really important support system for me.” Students relied on friends for support, but also recognized the importance of not burdening peers with disability related concerns. Lucy made one close friend in her dorm and commented, “I don’t know how she has stepped into this role, but we have grown closer and have been each other’s person to talk to about our struggles.” Additionally, students depended on therapists and counselors for support while navigating anxiety disorders. When these students felt supported, they were better able to self-advocate.

Not only did students with anxiety disorders require human support, but they also needed support in the form of academic accommodations. All students in this study relied on academic accommodations provided through disability services. According to Erin, “It’s leveling the playing field because it takes me a longer time to process and comprehend things than somebody who does not require accommodations.” Students articulated that accommodations allowed for everyone to have equal opportunities.

Students encountered discrimination when peers and faculty exhibited negative behaviors in relation to accommodations. Shannon provided an example of peer negativity when a classmate announced, “I wish I could have accommodations so I could have extra time—that’s not fair.” These types of statements were upsetting to students, including Shannon, who described the time-consuming process of obtaining accommodations. Other students shared how peers thought accommodations provided them an advantage or that they were “hacking the system.” In terms of faculty, students tried to limit their interactions and preferred to email testing forms to avoid conversations or confrontation. Since their disabilities were primarily invisible, students felt that others were more apt to question the validity of their disabilities and accommodations.

Student interviews revealed thoughtful and complex perceptions of self-advocacy, and each student’s self-advocacy journey included multiple layers. As students reflected on their life histories, discussions about self-advocacy continued.
The Occupational Profile Template

Students shared life stories while answering questions from the Occupational Profile Template in order to address the second research question: how does self-advocacy impact occupational engagement as related to the student’s college experience? This process allowed students to discover occupational successes and barriers within the college environment. The most challenging daily life activities that were impacted by self-advocacy were: health management, education participation, social participation, sleep participation, and communication management (see Figure 2).

Health Management

It was not easy for students with anxiety disorders to take the initial step to disclose health concerns to parents, teachers, or medical professionals, but acknowledging the need for help was an important step in their self-advocacy journey. This essential, yet difficult, first step required students to speak up about how they were feeling and functioning within their environments. According to Tara, it was a “complicated process getting the diagnosis.” Students were often misdiagnosed initially and then received additional diagnoses over time. Among study participants, there was a high level of comorbidities, including anxiety disorders, attention deficit hyperactivity disorder (ADHD), obsessive compulsive disorder (OCD), post-traumatic stress disorder (PTSD), depression, bipolar disorder, eating disorder, and autism spectrum disorder (ASD). Each individual experienced anxiety differently. Often, it was difficult to know which diagnosis was impacting which activity or task (see Table 4).

Besides obtaining a diagnosis, receiving the correct medication and/or dosage often required multiple visits with the physician. Erin stated that it was “hard to find the right medications and doses.” Returning to physicians required students to self-advocate for their health and well-being. Kelly stated, “I know for a fact I could not be where I am now without my medication.” Most students reported that medication was a critical component in their ability to function.

Education Participation

When students with anxiety disorders are struggling academically, they have the option to self-advocate and disclose their disabilities to disability service professionals and receive accommodations. All students in this study received academic accommodations; nevertheless, most expressed difficulties with participation in education. Kelly stated, “education is the main concern and always has been. It’s very difficult being a student with all of the disorders I have.” Educational difficulties included trouble maintaining focus in class or with assignments, studying, completing coursework, becoming overwhelmed with assignments, and taking exams. According to Lucy, “My anxiety, as well as some other factors, can make school work very hard.” Many students reported increased anxiety surrounding academics. Rachel stated, “Under normal circumstances, I’m pretty productive, but once I get to the point where I’m so overwhelmed, I can’t do anything, and I don’t know where to start.”

Social Participation

An anxiety disorder can negatively impact a college student’s social participation. Social concerns included fitting in or belonging, meeting and talking to new people, and finding the time to socialize especially when academic burdens were so great. Some students chose down time over socialization especially when exhausted and overwhelmed by academic demands. Shannon advocated for her social needs by taking the time to “calm down, relax and do nothing.” While it was necessary for Shannon to decrease social experiences, other students desired additional opportunities. Henry expressed frustration with social participation as it had always been an issue. He described how he was “really aching for social experiences.” Additionally, Rachel desired to be “more comfortable around others” as she was often concerned about what others thought of her. Students in this study had varying degrees of social participation, impacted by multiple diagnoses and the ability to self-advocate.

Sleep Participation

Falling asleep or sustaining sleep without disruption was a common theme for students in this study. Sleep participation has been a struggle for most students throughout their life and many have relied on supports. Students self-advocated when they acknowledged sleep difficulties and sought assistance. Supports included weighted blankets, melatonin, guided meditation, and altering the lights and sounds of their sleep environments. Kelly, Erin, Lucy, and Rachel all reported using weighted blankets as valuable additions to their sleep routine. According to Kelly, the blanket “helps with panic attacks, anxiety attacks, if I just can’t fall asleep, or if I’m stressed... and I can’t put a finger on it. I’ll put it on, and I feel so much better. I feel relief right away.” Other students excelled at creating boundaries and had strict routines associated with sleep. Kate was careful to not let anything ruin her sleep schedule. By advocating for sleep needs, some students’ daily life activities were limited including education participation, social participation, and communication management.
Figure 2

Conceptual Diagram to Illustrate the Themes of Challenging Daily Life Activities/Occupations

Note. Conceptual diagram illustrating how themes pertaining to the second research question, “How does self-advocacy impact occupational engagement as related to the student’s college experience?”
Table 4

**Participant De-Identified Demographics: Age, Gender, and Diagnosis**

<table>
<thead>
<tr>
<th>Assigned number &amp; pseudonym</th>
<th>Age/Gender</th>
<th>Diagnosis</th>
<th>Age of diagnosis and/or onset of anxiety</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 – Kelly</td>
<td>19/F</td>
<td>Anxiety, ADHD, OCD, Dysthymia</td>
<td>Onset: 6th grade Diagnosis: Sophomore in high school</td>
</tr>
<tr>
<td>2 – Kenneth</td>
<td>31/M</td>
<td>Anxiety, Panic Disorder</td>
<td>Diagnosis: 27 years old but felt anxiety earlier</td>
</tr>
<tr>
<td>3 – Erin</td>
<td>21/F</td>
<td>Anxiety, ADHD, Depression, Excoriation, OCD, OCD, Panic Disorder, Trichotillomania</td>
<td>Diagnosis: 15 years old but felt like she was struggling for a long time before</td>
</tr>
<tr>
<td>4 – Lucy</td>
<td>19/F</td>
<td>Anxiety, ADD, Depression</td>
<td>Diagnosis: Sophomore in high school</td>
</tr>
<tr>
<td>5 – Henry</td>
<td>23/M</td>
<td>Anxiety, Depression, Pervasive Developmental Disorder</td>
<td>Diagnosis: Freshman in high school</td>
</tr>
<tr>
<td>6 – Shannon</td>
<td>22/F</td>
<td>Anxiety, Heart Arrhythmia, OCD, Panic Attacks</td>
<td>Diagnosis: Freshman year in college but had symptoms since kindergarten</td>
</tr>
<tr>
<td>7 – Tara</td>
<td>21/F</td>
<td>Anxiety, ADHD, Depression</td>
<td>Diagnosis: 16 years old</td>
</tr>
<tr>
<td>8 – Rachel</td>
<td>19/F</td>
<td>Anxiety, Depression, Eating Disorder, Social Anxiety</td>
<td>Onset: 7th grade Diagnosis: Senior year of high school</td>
</tr>
<tr>
<td>9 – Kate</td>
<td>21/F</td>
<td>Anxiety, PTSD</td>
<td>Diagnosis: Freshman year of college but always felt anxious</td>
</tr>
<tr>
<td>10 – Carrie</td>
<td>22/F</td>
<td>Anxiety, Depression, Panic Disorder, Bipolar Type 1</td>
<td>Onset: 12 years old Diagnosis: 17 years</td>
</tr>
</tbody>
</table>

*Note.* The study participant was assigned a number and pseudonym. The age, gender, diagnosis and onset were self-reported by study participants.
Communication Management

When discussing communication management, students focused on the virtual world and included both positive and negative aspects of communication. The positive elements they identified included emailing, texting, and videotelephony (video chat, Facetime, etc.). The benefits of email and text as opposed to face-to-face communication included the opportunity to process information and provide a well-thought-out response. Some students worried about saying the wrong thing, offending, or hurting others’ feelings. Additionally, students preferred communicating with professors about accommodations over email. They wished to avoid confrontation or to avoid being challenged about their accommodations. Students in this study were also very connected to family members, and videotelephony allowed them to stay in close contact with family and friends at any time. Kate stated, “It’s wonderful to be able to contact parents via text or Facetime. I rely on that a lot throughout the week.” Many students checked in daily with family members.

Students identified social media as the primary negative aspect of virtual communication. Using social media could be overwhelming and difficult to manage. Students reported that having to monitor excess information about another individual’s life was distracting, a waste of time, and anxiety inducing. According to Carrie, “I feel like social media is not productive. I don’t like scrolling and looking at what people are doing. I feel like that makes me feel worse about myself.” Students reported that when they distanced themselves from social media or took breaks, they felt more present.

The students in this study shared sincere stories about life as a college student with an anxiety disorder. As the stories unfolded, it became evident that self-advocacy had an influence on students’ daily life activities. Some students were able to self-advocate in their daily life activities while others were in the early learning stages of self-advocacy. The ability to self-advocate mirrored definitions from the literature. Although students were able to interpret and reflect five significant daily life activities/occupations which students considered challenging. Students in this study did not participate in formal instruction. They developed self-advocacy skills with support and instruction from parents and teachers and by experiencing failures and successes throughout the process.

All study participants unanimously affirmed that self-advocacy was an important and essential skill to acquire and maintain. Student interpretations of self-advocacy mirrored definitions from the literature. Although students were able to interpret and recognize the value of self-advocacy, it was burdensome for most. The thought of self-advocating mainly elicited negative feelings. Students explained experiences regulating physical and emotional feelings linked with anxiety in addition to the negative feelings associated with self-advocating. Student diagnoses and personal experiences were unique to each individual; therefore, each participant was at a different phase in their self-advocacy journey.

Occupational Profile Template

The data from the Occupational Profile Template reflected five significant daily life activities/occupations which students considered challenging. Students with anxiety disorders certainly experienced specifically anxiety disorders. The present study uncovered students’ perceptions of self-advocacy and self-advocacy’s relationship to daily life activities. All participants openly shared stories about their experiences as individuals with anxiety disorders. The researcher used open-ended self-advocacy questions and the Occupational Profile Template to form a comprehensive understanding of the students. The data collection strategies allowed the researcher to discern student successes and barriers within the college environment. Additionally, EHP, the chosen framework, guided the study and was reflected in the holistic student narratives. Interdependent person/context relationship influences how the students are able to perform by engaging in tasks, which impacts the college experience. The remainder of this section discusses the themes gleaned from the open-ended self-advocacy questions and the Occupational Profile Template.

Self-Advocacy Questions

As discussed earlier, self-advocacy is a learned skill which is not easy for many college students. According to Daly-Cano et al., (2015) “In learning a skill such as self-advocacy, it is important to acknowledge that many students will not use this skill without deliberate and repeated instruction” (p. 222). Numerous factors impacted students’ abilities to self-advocate and influenced where they positioned themselves in their journey. Students in this study did not participate in formal instruction. They developed self-advocacy skills with support and instruction from parents and teachers and by experiencing failures and successes throughout the process.

As the population of students with disabilities who attend a college or university continues to increase, additional resources are vital to support these individuals. Students agreed to participate in this study for a variety of reasons, but the primary motivator was a desire to contribute to the greater good for the sake of improving the college environment for future students with mental health disabilities, and specifically anxiety disorders. The present study uncovered students’ perceptions of self-advocacy and self-advocacy’s relationship to daily life activities. All participants openly shared stories about their experiences as individuals with anxiety disorders. The researcher used open-ended self-advocacy questions and the Occupational Profile Template to form a comprehensive understanding of the students. The data collection strategies allowed the researcher to discern student successes and barriers within the college environment. Additionally, EHP, the chosen framework, guided the study and was reflected in the holistic student narratives. Interdependent person/context relationship influences how the students are able to perform by engaging in tasks, which impacts the college experience. The remainder of this section discusses the themes gleaned from the open-ended self-advocacy questions and the Occupational Profile Template.
success; however, the daily life activities which students found problematic within the college environment further informed this study. The five daily life activities included health management, education participation, social participation, sleep participation, and communication management.

Health management includes obtaining correct diagnoses and correct medications. In order to receive an initial diagnosis and/or medication, the student needed to self-advocate by seeking help. Most continued discussions with parents, teachers, and professionals to alter diagnoses and medications. Some students continued to uncover new diagnoses and changed medications. Self-advocacy is and will be required throughout students’ lives as they manage their health.

Education participation is difficult; the educational experience can be overwhelming for a variety of reasons including accomplishing academic requirements and the self-advocacy needed to accomplish desired tasks. However, students are more accustomed to advocating for their academic needs as opposed to other occupational needs. All students in this study received academic accommodations through disability services. Disclosing a diagnosis was one more steppingstone in the student’s self-advocacy journey as opposed to those who had not registered with disability services. Most students preferred, simply, the responsibility to disclose to disability services; however, students are expected to go one step further and discuss accommodations with professors. Students often avoided face to face contact with professors and sent accommodation letters or testing requests via email. Even though students received academic accommodations, they continued to struggle with completing assignments and exams and maintaining focus.

Some students were satisfied with social participation, yet most students found socialization to be complicated. Obstacles to socializing occurred for multiple reasons. For example, the symptoms associated with anxiety disorders disrupted student’s opportunities for peer interaction. Physical and emotional symptoms of anxiety required students to take frequent breaks from academics and activities and to remove themselves from social situations. The literature stated that students with disabilities commonly choose social acceptance over academic success when accommodations contribute to being socially isolated from peers or being labeled as a person with a disability (Hong, 2015). However, in this study, students chose sleep or education related daily life activities over social participation out of necessity. Making these difficult decisions required self-advocacy.

While students desired socialization, the practicality of getting adequate rest and completing academic requirements outweighed social participation.

Most students reported struggling with sleep at some point in their lives. Students self-advocated when they prioritized sleep and chose to seek out supports to encourage successful sleep participation. As discussed, four students used weighted blankets to facilitate calm and restful sleep experiences. Students preferred natural remedies such as meditation, white noise and altering the lighting, over prescription sleep medications.

Some students found communication management positive, while others found it a struggle. The virtual world provided a considerable amount of communication, and students had mixed feelings about that. Students generally preferred emailing and texting over face-to-face communication as it allowed additional time to process and formulate suitable responses; they also preferred videotelephony for communicating with close friends and family members. Students in this study relied heavily on frequent family support, overwhelmingly from mothers, and this was best achieved through texting and videotelephony whenever necessary. Interestingly, most students found social media to be an unfavorable and ineffective form of communication. Often, social media elicited negative feelings. Students benefited from self-advocacy when choosing the most appropriate form of communication and when recognizing the need to make changes or take breaks from the virtual world.

Limitations

While this research provided an abundance of data for present and future studies, limitations do exist. One limitation is that due to criterion sampling, the findings could not necessarily be generalized to a larger population of all college students with anxiety disorders. A second limitation is the lack of diversity among participants: as 8 of the 10 students identified as female, all ranged in age from 19-31, and all attended a private, religiously affiliated university in the Midwest. A third limitation was the time parameters of this study; follow up with students could provide additional insights into the study’s efficacy.

Implications

The results of this study offer a variety of opportunities for future research and programming for disability support professionals and an interdisciplinary team. Both the current data and literature suggest that students will benefit from self-advocacy programming as it is a learned skill and not intuitive for most students.
Considering the challenges students with anxiety disorders face communicating with professors and peers, instruction from a practitioner on how to self-advocate may help decrease barriers. Programming for students may be best implemented through a collaborative and interdisciplinary approach. The interdisciplinary team may include individuals from disability services, occupational therapy, counseling, the health center, residence life, and the dean of students office.

An interdisciplinary team would add valuable insights to assist with the surge of students with disabilities and already stressed resources. When considering self-advocacy programming, the team can help students realize how to best manage their daily life activities in college, especially education participation and communication, to foster more positive and productive academic relationships.

Further, the current study helped reinforce that learning how to self-advocate is difficult, it produces positive and negative feelings, and students with anxiety disorders must also manage the physical and emotional symptoms associated with their anxiety disorder. An interdisciplinary team is well suited to create holistic self-advocacy programming to address the skills and feelings surrounding self-advocacy and to recognize how symptoms of anxiety impact daily life activities within the college environment. While this study focused on anxiety disorders, evidence in the literature suggests that a wide variety of students with disabilities struggle with self-advocacy; therefore, this programming may serve a larger and more inclusive population.

Beneficial strategies may include focus groups or peer groups to discuss student concerns and needs and role-play activities and instruction based on self-advocacy development. Self-advocacy programming may also be offered as a recommended workshop prior to beginning course work at the college or university. Additionally, an interdisciplinary team can benefit students by participating in college or university panels that target student health and wellness, campus life, and navigating academics. Panels may include disability support professionals, an occupational therapy practitioner, campus counselors, practitioners from student health, and administrators from residence life and the dean of students office. The team would provide a holistic perspective and diverse expertise that targets the daily life activity barriers discussed in this research.

Next, an interdisciplinary team can work together to utilize the guiding framework of this study, the Ecology of Human Performance (EHP), to its full extent by incorporating the five intervention approaches when working with students with disabilities in higher education. After completing student interviews, follow-up meetings with each student would be beneficial to discuss interview results and implement a student-centered intervention plan. The EHP intervention approaches address the person, context, and task in order to enhance the student’s skills, accommodate the environment, prevent problems from occurring, and proactively look for ways to improve performance within the context for all individuals (Dunn et al., 1994).

The interdisciplinary team may work with the student to develop strategies for turning daily life activity barriers experienced in college into successes. A few examples include the following:

- Role-playing with the student to practice self-advocacy with professor-student interactions regarding accommodations
- Develop groups to explore the feelings associated with self-advocating and the impact on participation in daily life activities
- Assisting with health concerns related to symptoms of anxiety and comorbidities
- Developing academic strategies to promote efficient study practices
- Assessing residence halls, classrooms, cafeterias, and other campus buildings to determine the best access and the most comfortable experiences
- Assisting with daily scheduling to help students enhance social experiences and sleep
- Creating peer groups to practice communication management and socialization

The above examples offer flexible opportunities for individual and group interventions and may occur with one or more members of the interdisciplinary team.

Another consideration is that all students in this study discussed the importance of parents as support systems while navigating the college environment. Based on this study, students relied heavily on parental support. Parent perspectives may provide additional insight into the student’s ability to self-advocate and participate within the college environment. Additionally, an interdisciplinary team may create workshops and materials on how parents can support their student during this transition and new phase of life. A transitional workshop could be offered simultaneously with the student self-advocacy workshop prior to beginning their initial coursework.
References


**About the Authors**

Amy Hasman received her B.S. in occupational therapy from Saint Louis University and O.T.D. from Saint Louis University. Her experience includes working as a pediatric occupational therapist, adjunct professor, and disability support provider. She is currently a Disability Specialist for St. Louis Community College and an adjunct professor for the Department of Occupational Science and Occupational Therapy at Saint Louis University. Her research interests include mental health and well-being for college students with disabilities, universal design and sensory processing. She can be reached by email at: ahasman@stlcc.edu.

Cynthia Matlock received her B.S. in occupational therapy from University of Missouri and Ph.D. from Saint Louis University. Her experience includes working as an occupational therapist in the areas of mental health, adult physical disability, and academia. She is currently an Associate Professor at Saint Louis University in the Department of Occupational Science and Occupational Therapy. Her research interests include student perspectives of professional behavior and attitude development, and diversity, equity and inclusion in the occupational therapy profession. She can be reached by email at: cynthia.matlock@health.slu.edu.
Setting Students up for Success:
Academic Skills Before and After Participation in 2-4-8,
a Proactive Advising Model for Students with Disabilities

Caitlin A. Rothwell¹
Joseph J. Shields¹

Abstract

Disability support (DS) offices provide accommodations for and serve qualified students with disabilities. The overall number of students with disabilities in higher education is increasing, creating a need for high-impact, effective support. Proactive advising is a method of support that provides college students tools for success before crises occur. Most proactive advising for students with disabilities focuses on a narrow population (e.g., students with ADHD or learning disabilities). However, DS offices serve a diverse array of diagnoses. 2-4-8 is a proactive advising model in which all students with documented disabilities meet individually with a DS staff member at least three times in the fall semester to ensure that accommodations, supports, and skills necessary for success in higher education are in place. This study was a preliminary investigation of perceived academic skills before and after participation in 2-4-8. Initial findings indicate that self-reported organization, time management, professor communication, and studying were significantly improved through 2-4-8, and that perceptions of test taking, self-advocacy, and meeting deadlines were slightly, though non-significantly, improved. This study provides promising evidence that 2-4-8 could be a useful resource to provide proactive, quality support that meets the diverse needs of college students with disabilities.

Keywords: academic skills, proactive advising, students with disabilities, 2-4-8

Since the passing of the Americans with Disabilities Act in 1990, higher education institutions have been mandated to provide accommodations for students with disabilities. In 2008, 88% of higher education institutions reported enrolling students with disabilities (Raue & Coopersmith, 2011). The vast majority of colleges and universities have since created a disability support (DS) office to provide accommodations and services for students with disabilities. These offices serve a significant portion of the student population. Overall, about 19% of undergraduates report having a disability (Snyder et al., 2019). In a review of students with disabilities across college campuses, an average of 271 students were registered with the DS office at medium-sized colleges (1,500 - 9,999 total students). However, the number of students registered with the DS office ranged from 17 to 1,300 (Scott, 2017). This significant variation between universities makes it difficult to generalize how many students with disabilities utilize support from a DS office at any given institution. Nonetheless, the overall number of students with disabilities is increasing across university populations (Easby & Hamilton, 2019; Sachs & Schreuer, 2011). With an increasing number of students receiving services through a DS office, DS offices must ensure they are supporting students efficiently and effectively.

DS offices support students with a wide range of disabilities, which can span from mental health issues, to sensory impairments, to learning disabilities, to executive dysfunction, to traumatic brain injuries, to chronic health conditions, to autism spectrum disorders (ASD), and to physical impairments. Similar to the range in number of students registered with a DS office, the range of disabilities, impairments, and strengths varies widely among students. DS pro-

¹ The Catholic University of America
fessionals must have a good understanding of all disabilities so they can tailor support to a student’s individual strengths and challenges (D’Alessio & Banerjee, 2016).

Students with disabilities are at higher risk than their non-disabled peers; they are more likely to drop out before attaining a degree and to take longer to attain a degree (Becker & Palladino, 2016; Hinz et al., 2017). While all students encounter challenges in higher education, students with disabilities experience additional challenges rooted in their disability (Hong et al., 2007). For example, a student with a learning disability may need more time to process and learn new information in classes than their non-disabled peers, or a student with a chronic health condition may need to spend more time addressing their health before attending to academics.

DS offices are created to serve this high-risk community. Yet, DS staff also often feel overwhelmed. In a survey sent to DS staff members, only a third of respondents reported that their workload was just right and more than half of respondents reported they spend time outside of office hours to complete basic work (Scott, 2017). These statistics reveal that DS staff continually feel behind in their work to support a high-risk population.

Given that DS offices are tasked with providing accommodations and supporting students with disabilities, that the number of students with disabilities is increasing, that students with disabilities are more likely to struggle compared to their non-disabled peers, and that DS staff often feel behind in their work, more attention must be paid to how DS offices support students with disabilities.

**Proactive Advising and Academic Skills**

Academic skills are conceptually defined by behavioral, attitudinal, and problem-solving skills that allow students to be successful in the academic environment. All college students, no matter the presence of disability, must have academic skills to excel in higher education. While some students enter college with all of the academic skills necessary for success, others require additional guidance to learn academic skills. Students with disabilities are more likely to need such guidance because they encounter additional challenges rooted from their disability.

Students with disabilities were more likely to successfully complete college if they utilized extracurricular supports (Los Santos et al., 2019; Newman et al., 2019). Proactive advising is a common form of extracurricular support. In proactive advising, sometimes also called academic advising, intrusive advising, or academic coaching, an advisor or qualified staff member works with a student on skills that are considered essential to academic success. While proactive advising has multiple models and approaches, overall the focus is to assist students with identified disabilities to gain the skills necessary for academic success (D’Alessio & Banerjee, 2016). These skills are categorized under academic skills.

What topics do proactive advising cover? In a qualitative study, students with disabilities were asked what topics proactive advising should cover. Themes from their responses included campus integration, experience in disability management and adaptation, and academic strategies (Fleming et al., 2018). Similarly, in a review of topics covered in proactive advising with students with disabilities, the areas of time management and utilization of resources were frequently highlighted (Button et al., 2019). These topics can also be encompassed by skills that typically fall under the domain of academic skills. Academic skills include a combination of learning strategies, such as study skills and reading strategies, and psychosocial strategies, such as self-advocacy and motivation. Academic skills, covered in proactive advising, are essential for academic success in higher education.

Although some research points to the potential benefits of proactive advising, little research has been conducted to determine the outcomes of proactive advising for students with disabilities. Some research suggests that participation in group-based proactive advising decreases severity of Attention Deficit Hyperactivity Disorder (ADHD) symptoms and increases use of academic skills (LaCount et al., 2015; Stevens et al., 2019). One study investigating proactive advising for students with ADHD and learning disabilities found that students who received proactive advising had higher GPAs that those who did not receive such support (Du Paul et al., 2017). Most of the research in this area focuses on the needs of students with ADHD and learning disabilities whereas all students with disabilities need to have core adult learning skills to be successful in higher education.

**2-4-8 Proactive Advising Model**

2-4-8 is a proactive advising model designed to fill this gap by teaching academic skills to college students with any disability. In 2-4-8, students with documented disabilities meet individually with a DS staff member at least three times in the fall semester to ensure all accommodations, supports, and skills necessary for success are in place. 2-4-8 is named thusly because students meet individually with a DS staff member two, four, and eight weeks after receiving their letter of accommodation. These Week
2, Week 4, and Week 8 meetings are the minimum; students can meet with DS staff at other times to follow up on a specific issue or work on a skill targeted in a 2-4-8 meeting.

Students with many different categories of disabilities participate in 2-4-8. Categories of disabilities range from ADHD, to sensory impairments, to mental health disorders. To ensure that each student’s unique needs are met, it is vital for staff to understand disability and tailor support to each individual student (D’Alessio & Banerjee, 2016). This need for tailoring is why 2-4-8 is housed in the DS office and not in other student support offices, such as advising or tutoring.

The 2-4-8 model has several overarching goals, including (a) ensuring that each student has the academic and organizational skills necessary for success, (b) confirming that each student understands and utilizes accommodations and supports, and (c) building a rapport with each student so that the student comes back before a moment of crisis.

To ensure that all students enrolled in 2-4-8 meet these goals, Week 2, Week 4, and Week 8 meetings have a semi-structured interview format. Each meeting includes a list of preset questions tailored to meet the individual needs of students. The structure of Week 2 meetings is more rigid than the subsequent meetings; Week 4 and Week 8 meetings allow for more individual follow-up based on discussions in previous meetings. This format ensures that all students are asked about fundamental academic skills, while also allowing for personalization to meet the strengths and needs of each individual student. In Week 2, Week 4, and Week 8 meetings, DS staff members ask students questions about academic skills, such as organization, professor communication, time management, studying, meeting deadlines, self-advocacy, test taking, family communication, motivation, and writing. The questions that DS staff ask students that get to these academic skills include: How are you going to organize yourself and remember all due dates this semester? Are you using your organizational system each day? What other campus supports do you believe you will need to utilize this semester? Have you begun using these supports, and if so, were these meetings effective? How are you utilizing your accommodations for each class? How do you plan to study for your upcoming test? What is your plan to write a paper due soon? Have you been late to any classes? Have you been able to turn in assignments on time? If not, what was the issue that impeded you meeting your deadline? How can we resolve this issue? Have you gotten any grades or professor feedback yet? Do you know how to communicate with your professor if you have any concerns about your feedback? Have you discussed with your family what feedback you have received?

The three required meetings are a balance between the average of 1-2 meetings a DS staff has with a student each semester (Scott, 2017) and the average seven meetings between an academic coach and a student each semester (Button et al., 2019). The number of three meetings as a minimum requirement balances quality with quantity, and the spread of these meetings over half of a typical semester allows the DS staff member to get to know and build rapport with each student on an individual level. The three required meetings also allow for DS staff to have a higher caseload than an academic coach who may be required to meet every other week with a student throughout the semester.

All meetings are conducted individually for 30 minutes. This meeting time length allows for the balance between meeting an individual student’s needs and supporting as many students as possible (Scott, 2017). Students are expected to prepare for each meeting, and are emailed instructions on how to prepare for each meeting a week before the meeting.

If, after the student completes the three required meetings, there are no indicators of potential issues and there is no follow-up required or requested, the staff member then discusses with the student how to continue seeking support if they wish. Most often, there are a few follow-up meetings to work on academic and organizational skills that need improvement. These skills most often involve time management, study skills, test taking strategies, organization of major assignments, and communication with professors.

2-4-8 is a unique proactive advising model for college students with disabilities because it serves students with any type of disability. It has the potential for DS to provide quality support to a high volume of high-risk students. Research to date indicates that proactive advising is useful for students with disabilities. To begin examining the effectiveness of this proactive advising model, descriptive and correlational analyses examined perceptions of academic skills before participation in 2-4-8. Then academic skills before and after participation in 2-4-8 were compared. This study asked: What do academic skills look like in students with disabilities? Is there an increase in academic development after participation in 2-4-8? If so, which academic skills are increased? The academic skills investigated here include self-reports of organization, professor communication, time management, studying, meeting deadlines, self-advocacy, test taking, family communication, motivation, and writing.
Methods

Procedure

To begin assessing the effectiveness of the 2-4-8 proactive advising model, a pragmatist paradigm was utilized for this non-experimental, longitudinal, correlational design. In this study, components of descriptive and correlational analyses were used to assess academic skills before and after participation in 2-4-8.

All students who participated in 2-4-8 were qualified, current students; they were eligible to receive accommodations and requested to receive accommodations in the current semester. All students who were enrolled in the 2-4-8 program and were 18 or older were invited to participate in the study via email. All research procedures were approved by the University's Institutional Review Board. This study included two self-report surveys that were emailed to potential participants before meeting with DS staff through 2-4-8 and at the end of the semester. The pre-survey was sent to enrolled students before their first 2-4-8 meeting. The pre-survey collected demographic information and self-perceptions of level of expertise in academic skills. An invitation to participate in the post-survey was sent to enrolled students at the end of the semester. The post-survey collected information about changes to their disability-related symptoms and another self-evaluation of academic skills. Students did not need to complete the previous surveys to participate. For example, a student could participate in the post-survey only. All participants were assigned a randomized subject ID code and data were analyzed after the completion of the semester. This protected the confidentiality of students. DS staff did not know if the students they worked with participated in the study and researchers were not knowledgeable of student identity when conducting analyses.

Statistical Analysis Plan

Academic skill information collected through the pre- and post-surveys were investigated in this study. Participants self-reported expertise with each academic skill on the 5-point Likert scale (1=specific weakness, 5=particular strength). Participants were also asked on the post-survey which skills they perceived were increased through participation in 2-4-8. The academic skills that participants self-evaluated included organization, writing, test taking, studying, time management, professor communication, family communication, self-advocacy, motivation, and meeting deadlines. Operational definitions of each academic skill are as follows:

1. Organization: choosing and implementing a single organizational method to stay on top of all assignments
2. Writing: transposing thoughts effectively into the written word
3. Test Taking: utilizing correct test taking strategies during a timed examination
4. Studying: organizing time to effectively and efficiently study and choose methods of studying best suited for test and subject matter
5. Time Management: organizing time and balancing academic and social demands to provide enough time to complete each task
6. Professor Communication: student-driven communication with professor regarding disability accommodations and course content
7. Family Communication: communication with family about academics
8. Self-advocacy: student-driven communication to advocate for academic needs
9. Motivation: identifying motives to complete assignments and stay on task
10. Meeting Deadlines: turning in assignments on time.

While most academic skills were targeted in 2-4-8, the skill of writing was not targeted. This variable provides a look into discriminant validity; writing should not be increased through participation in 2-4-8 as it was not targeted in the 2-4-8 model. Additionally, some academic skills are emphasized more through 2-4-8. While some skills (e.g., time management, organization, professor communication, meeting deadlines, and self-advocacy) are heavily targeted at all 2-4-8 meetings, other skills (e.g., test taking, family communication, motivation, and studying) are discussed in only one 2-4-8 meeting and not as heavily emphasized. Certain skills are emphasized more because they are both crucial for academic success and often decreased in students with disabilities.

Each academic skill was investigated in three ways to provide a comprehensive investigation of self-perceptions of these academic skills. First, academic skill perceptions were assessed by the percentage of students who responded that the academic skill was increased through participation in 2-4-8. Second, the percentages of students who rated each academic skill as a strength or particular strength on the pre- and post-surveys were compared. Finally, a paired-samples t-test was conducted for each academic skill to determine statistical significance.
Participants

In Fall 2018, 156 students were enrolled in 2-4-8 at a medium-sized private university in the Mid-Atlantic region and were eligible for participation. From this population, 87 students responded to the pre-survey and 47 students responded to the post survey. However, only 37 of the participants responded to both the pre- and post-survey. This study’s sample included the 37 participants who responded to both pre- and post-surveys.

This sample was split equally by gender (51.35% of participants identified as male and 48.64% as female). The majority identified as White (72.97% identified as White, 18.92% as African-American, 10.81% as Hispanic, 5.41% as Asian, and 2.72% as Middle Eastern). Respondents were allowed to respond to more than one category for race. Half of the participants were first year students (51.35% freshman, 18.92% sophomore, 16.22% junior, 13.51% graduate). Respondents were diagnosed in a number of distinct yet non-exclusive disability categories: 48.65% of students responded they were diagnosed with and receiving services for ADHD, 48.65% learning disability, 27.03% psychological disability, 13.51% ASD, 5.41% visual impairment, 5.41% hearing impairment, 5.41% mobility impairment, and 2.70% traumatic brain injury. Over one third (37.84%) self-identified as having diagnoses in two or more disability categories. It is also important to note that disability symptoms were not stagnant; 21.62% of students reported experiencing a change in their mental or physical health during the semester.

The majority of this sample completed all 2-4-8 meetings (83.78%) while a few (16.22%) partially completed the program with one or two meetings. Overall, the majority of students (56.76%) met with DS more than the three required meetings and a third (35.14%) met with DS staff weekly. When asked if they found 2-4-8 helpful, 78.38% of respondents reported that 2-4-8 was helpful. Most importantly, all but one student (97.39%) would recommend 2-4-8 to an incoming student. Even if a student did not find it helpful, they would recommend it to an incoming student. This shows that students still see the value in the program even if it didn’t help them personally. From this sample, only 8.11% withdrew from one or more classes. This is in part because students utilized the assistance of other support offices on campus when necessary. 91.89% of students utilized support outside of DS (72.97% reported using professor office hours; 51.35% Writing Center; 37.84% Counseling Center; 29.73% tutoring; 27.03% Math Center).

Results

First, students were asked what academic skills they believed had increased through participation in 2-4-8. See Table 1 for a visual representation of the number and percentage of participants who responded that skills had increased on the post-survey. The majority of the students responded that time management (67.74%), organization (61.29%), and professor communication (58.06%) had increased through participation in 2-4-8. Many students also responded that meeting deadlines (45.16%), self-advocacy (45.16%), test taking (41.94%), and studying (41.94%) had increased through participation in 2-4-8. Few students responded that writing (19.35%) and family communication (12.90%) were increased through participation in 2-4-8. Writing and family communications are not emphasized in 2-4-8, and therefore the small percentages of students reporting growth in these areas supports the validity of these data.

Second, the difference between the percentages of participants who responded that an academic skill was a strength or particular strength on the pre- and post-surveys was calculated. Table 2 includes a table of the percentages and the differences between pre- and post-survey responses. Organization and professor communication had the greatest increases for students who rated these skills as a strength after participation in 2-4-8. Over a fifth (21.72%) more students rated organization as a strength after participation in 2-4-8. Similarly, 21.62% more students responded that professor communication was a strength after 2-4-8. Other skills saw a modest growth for students who responded that the academic skill was a strength after 2-4-8: there was a 13.52% increase in time management, 13.51% increase in studying, 10.82% increase in meeting deadlines, and 10.81% increase in both self-advocacy and test taking. Only 2.70% more students responded that family communication had increased through participation in 2-4-8. Few students responded that motivation was a strength after 2-4-8. Other skills saw a modest growth for students who responded that the academic skill was a strength after 2-4-8: there was a 13.52% increase in time management, 13.51% increase in studying, 10.82% increase in meeting deadlines, and 10.81% increase in both self-advocacy and test taking. Only 2.70% more students responded that family communication had increased through participation in 2-4-8. Many students also responded that communication (58.06%) had increased through participation in 2-4-8. Few students responded that writing (19.35%) and family communication (12.90%) were increased through participation in 2-4-8. Writing and family communications are not emphasized in 2-4-8, and therefore the small percentages of students reporting growth in these areas supports the validity of these data.

Third, paired-samples t-tests were conducted for each academic skill to determine which skills were significantly changed after 2-4-8. Table 3 includes the results of all of the paired-samples t-tests. Organization and studying showed significant increases after 2-4-8. There was a significant difference in organization before (M = 3.46, SD = .96) and after 2-4-8 (M = 3.84, SD = .93); t(37) = -2.67, p = .01. Omega-square was utilized to calculate effect size, finding 14% of the variability in organization can be related to the difference in the mean amount of organization from the pre-survey to the post-survey. This is a medium effect.
### Table 1

*Academic Skills that Participants Responded were Increased Through Participation in 2-4-8 (n=37)*

<table>
<thead>
<tr>
<th>Academic Skill</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time management</td>
<td>21</td>
<td>67.74</td>
</tr>
<tr>
<td>Organization</td>
<td>19</td>
<td>61.29</td>
</tr>
<tr>
<td>Professor communication</td>
<td>18</td>
<td>58.06</td>
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<tr>
<td>Meeting deadlines</td>
<td>14</td>
<td>45.16</td>
</tr>
<tr>
<td>Self-advocacy</td>
<td>14</td>
<td>45.16</td>
</tr>
<tr>
<td>Test taking</td>
<td>13</td>
<td>41.94</td>
</tr>
<tr>
<td>Studying</td>
<td>13</td>
<td>41.94</td>
</tr>
<tr>
<td>Motivation</td>
<td>10</td>
<td>32.26</td>
</tr>
<tr>
<td>Writing</td>
<td>6</td>
<td>19.35</td>
</tr>
<tr>
<td>Family communication</td>
<td>4</td>
<td>12.90</td>
</tr>
</tbody>
</table>

### Table 2

*Percentage of Students Responding to an Academic Skill as a Strength or Particular Strength (n=37)*

<table>
<thead>
<tr>
<th>Academic Skill</th>
<th>% Pre-Survey</th>
<th>% Post-Survey</th>
<th>Post-Pre Difference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Organization</td>
<td>45.85</td>
<td>67.57</td>
<td>+21.72</td>
</tr>
<tr>
<td>Professor communication</td>
<td>56.76</td>
<td>78.38</td>
<td>+21.62</td>
</tr>
<tr>
<td>Time management</td>
<td>32.43</td>
<td>45.95</td>
<td>+13.52</td>
</tr>
<tr>
<td>Studying</td>
<td>27.03</td>
<td>40.54</td>
<td>+13.51</td>
</tr>
<tr>
<td>Meeting deadlines</td>
<td>64.86</td>
<td>75.68</td>
<td>+10.82</td>
</tr>
<tr>
<td>Self-advocacy</td>
<td>56.76</td>
<td>67.57</td>
<td>+10.81</td>
</tr>
<tr>
<td>Test taking</td>
<td>29.73</td>
<td>40.54</td>
<td>+10.81</td>
</tr>
<tr>
<td>Family communication</td>
<td>81.08</td>
<td>83.78</td>
<td>+2.70</td>
</tr>
<tr>
<td>Motivation</td>
<td>59.46</td>
<td>59.46</td>
<td>0.00</td>
</tr>
<tr>
<td>Writing</td>
<td>47.84</td>
<td>35.14</td>
<td>-12.70</td>
</tr>
</tbody>
</table>
Table 3

*Paired-Samples T-test of Academic Skills in the Pre- and Post-Surveys*

<table>
<thead>
<tr>
<th>Academic Skill</th>
<th>Pre-Survey</th>
<th></th>
<th>Post-Survey</th>
<th></th>
<th>t (36)</th>
<th>p</th>
<th>Omega Square</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
<td>M</td>
<td>SD</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Organization</strong></td>
<td>3.46</td>
<td>0.96</td>
<td>3.84</td>
<td>0.93</td>
<td>-2.67</td>
<td>0.01**</td>
<td>0.14</td>
</tr>
<tr>
<td><strong>Studying</strong></td>
<td>2.86</td>
<td>1.00</td>
<td>3.30</td>
<td>1.08</td>
<td>-2.46</td>
<td>0.02**</td>
<td>0.12</td>
</tr>
<tr>
<td><strong>Time Management</strong></td>
<td>2.81</td>
<td>1.20</td>
<td>3.19</td>
<td>1.18</td>
<td>-2.02</td>
<td>0.05*</td>
<td>0.08</td>
</tr>
<tr>
<td><strong>Professor Communication</strong></td>
<td>3.65</td>
<td>0.92</td>
<td>3.95</td>
<td>0.94</td>
<td>-1.93</td>
<td>0.06*</td>
<td>0.07</td>
</tr>
<tr>
<td><strong>Test Taking</strong></td>
<td>2.95</td>
<td>0.94</td>
<td>3.24</td>
<td>0.93</td>
<td>-1.87</td>
<td>0.07*</td>
<td>0.06</td>
</tr>
<tr>
<td><strong>Self-Advocacy</strong></td>
<td>3.59</td>
<td>0.87</td>
<td>3.84</td>
<td>1.12</td>
<td>-1.43</td>
<td>0.16</td>
<td></td>
</tr>
<tr>
<td><strong>Meeting Deadlines</strong></td>
<td>3.76</td>
<td>0.96</td>
<td>3.97</td>
<td>1.19</td>
<td>-0.94</td>
<td>0.35</td>
<td></td>
</tr>
<tr>
<td><strong>Motivation</strong></td>
<td>3.54</td>
<td>1.04</td>
<td>3.59</td>
<td>1.14</td>
<td>-0.39</td>
<td>0.70</td>
<td></td>
</tr>
<tr>
<td><strong>Writing</strong></td>
<td>3.11</td>
<td>1.05</td>
<td>3.14</td>
<td>1.16</td>
<td>-0.21</td>
<td>0.84</td>
<td></td>
</tr>
<tr>
<td><strong>Family Communication</strong></td>
<td>4.16</td>
<td>0.87</td>
<td>4.14</td>
<td>1.03</td>
<td>0.17</td>
<td>0.17</td>
<td>0.87</td>
</tr>
</tbody>
</table>

*Note.* **p ≤ .05, * .05 ≤ p ≤ .07
size according to Cohen’s criteria. There was a significant difference in studying before ($M = 2.86$, $SD = 1.00$) and after 2-4-8 ($M = 3.30$, $SD = 1.08$); $t(37) = -2.4, p = .02$. Omega-square was utilized to calculate effect size, finding 12% of the variability in studying can be related to the difference in the mean amount of studying from the pre-survey to the post-survey. This is also a medium effect size according to Cohen’s criteria. Finally, there was a difference, through trending in significance, in time management before ($M = 2.81$, $SD = 1.20$) and after 2-4-8 ($M = 3.19$, $SD = 1.18$); $t(37) = -2.02, p = .05$. There were also trending, yet non-significant increases in professor communication and test taking before and after participation in 2-4-8. There was no significant change in self-advocacy, meeting deadlines, motivation, writing, and family communication after 2-4-8.

Discussion

In an initial look at this sample, the demographics revealed that this sample was diverse, both in terms of diagnoses and experiences in higher education. This non-homogenous sample meant that some of the demographic information could have had unintentional impacts on results. However, the sample is also reflective of all students enrolled in 2-4-8 and the entire population that DS serves. One important strength of 2-4-8 is that this model serves all students with disabilities; it is not only for a subset of students that a DS office serves. 2-4-8 can help to reach the goal of ensuring that every student with a disability is off to a good start and has the academic skills and supports in place to succeed at the collegiate level.

The majority of student respondents found that 2-4-8 was beneficial. Even more importantly, almost every single respondent indicated that they would recommend 2-4-8 to an incoming student with a disability. This is strong evidence that even if a student did not find 2-4-8 personally helpful, they still saw its benefits for other students. This finding is also in line with the current body of research, which shows that proactive advising is helpful for students (e.g., Button et al., 2019; Fleming et al., 2018). Furthermore, because the overwhelming majority of participants would recommend 2-4-8 to an incoming student, it is worth the effort to implement and evaluate 2-4-8.

Throughout the analysis, three general tiers of academic skills emerged. The first tier of skills includes organization, time management, professor communication, and studying. The skills in the first tier were the main targets in 2-4-8 and showed the largest growth before and after enrollment in 2-4-8. The second tier of skills includes test taking, self-advocacy, and meeting deadlines, which showed modest, non-significant increases after participation in 2-4-8. The third tier of skills, consisting of motivation, family communication, and writing, includes those skills that were not increased after 2-4-8.

Organization was reported as the academic skill with the greatest increase after participation in 2-4-8; 61.29% of students reported that organization increased through 2-4-8 and 21.72% more students reported organization as a skill after 2-4-8. There was a significant increase in the average response for organization as a strength before and after 2-4-8 with a medium effect size. The reported increase in organization could be tied to sample demographics. Almost half of the respondents reported they were diagnosed with ADHD. Organization is a skill often impaired in students with ADHD, and a skill that is best targeted at the beginning of the semester. Because so many students struggled with organization and 2-4-8 occurred at the best time to target this skill, organization was the academic skill most impacted through 2-4-8.

Studying was also reported as improved after participating in 2-4-8; 41.94% of students reported that studying increased through 2-4-8 and 13.51% more students reported studying as a skill after 2-4-8. There was a significant increase in the average response for professor communication as a strength before and after 2-4-8 with a medium effect size. The percentage of students who reported that studying increased through 2-4-8 mirrors the percentage of the sample with a learning disability (48.65%). Students with learning disabilities not only need to learn how to study for each type of test, but also need to learn to study based on their strengths. Through 2-4-8, the DS staff member asks each student if they have an upcoming test and if so, how they are preparing. Oftentimes, the DS staff member works individually with students to find methods of studying that uniquely fit the type of test and the strengths of each student. Additionally, while students often enter college with study skills in place, these skills are not adequate for college-level courses and assessments. This discrepancy could be why there was a smaller addition of students who reported studying was a skill after 2-4-8, but still many students responded that studying increased through participation in 2-4-8.

Time management was also reported as significantly improved after participating in 2-4-8; 67.74% of students reported that time management increased through 2-4-8 and 13.52% more students reported time management as a skill after 2-4-8. There was a non-significant increase in the average response for time management as a strength before and after 2-4-8. Similar to organization, time management is
impaired in students with ADHD. Additionally, first-year students often struggle with the wide expanses of unorganized time in their first semester at college. Approximately half of the sample identified as being diagnosed with ADHD, and half of the sample indicated they were first-years. This combination could be why time management was improved so greatly through participation in 2-4-8.

The final skill in the first tier, professor communication, was also reported as improved after participating in 2-4-8; 58.06% of students reported that professor communication increased through 2-4-8 and 21.62% more students reported professor communication as a skill after 2-4-8. However, the increase in professor communication before and after 2-4-8 was only trending in significance. As discussed previously, about half of the sample included first-year students, who had not interacted with faculty in the higher education setting before 2-4-8. The 2-4-8 model specifically targets how to talk with professors both about general topics, such as implementing accommodations, and more specific topics related to course content. 72.87% of this sample also utilized professor office hours. The combination of learning skills in 2-4-8 and implementing them by utilizing professor office hours helps to set students up for success.

The second tier of skills includes test taking, self-advocacy, and meeting deadlines. This set of skills was targeted in 2-4-8 and saw modest, if not significant, growth after participation in 2-4-8. Students did report that these skills increased through 2-4-8 (41.94% reported test taking increased, 45.16% self-advocacy, and 45.16% meeting deadlines) and there were more students who reported these skills as a strength after 2-4-8 (+10.81% test taking, +10.81% self-advocacy, and +10.82% meeting deadlines). However, these improvements were not statistically significant. Improvements to the 2-4-8 model should target these academic skills so they can be improved further through participation in 2-4-8.

Finally, the third tier of skills includes skills that were not increased through participation in 2-4-8. This tier includes the skills of motivation, family communication, and writing. Few students reported that these skills were increased through 2-4-8 (32.26% reported motivation increased, 12.90% family communication, and 19.35% writing). There was little, no, or negative change in skills reported as a strength before and after 2-4-8 (+0% motivation, +2.70% family communication, and -12.70% writing). Finally, there was no significant change in response means before and after participation in 2-4-8.

Motivation was not reported as improved through 2-4-8, possibly because motivation was not targeted in 2-4-8. Future training for DS staff and modifications to 2-4-8 should target motivation, such as motivational interviewing. Motivation, while nebulous and difficult to pinpoint, is essential to success both in the academic setting and beyond.

Family communication included unique findings. The vast majority of students (81.08%) responded that family communication was a strength before 2-4-8, with 56.76% of students reporting that they spoke with family members at least every day. Given such high initial findings, there was no room for improvement, even though in the 2-4-8 program DS staff ensured that important academic information was relayed to family.

Writing was included as an academic skill in this study to provide discriminant validity. Writing is an academic skill that students with disabilities can work to improve, but is not targeted in 2-4-8, or even in the DS office. The university where this study was conducted has a Writing Center that is separate from the DS office but is trained by DS office staff to provide writing support to students with disabilities. In 2-4-8, students were referred to the Writing Center in the same way they were referred to the Counseling Center. Therefore, writing should not have improved through participation in 2-4-8. These non-significant findings further support the positive findings that 2-4-8 improved academic skills targeted in the program.

This preliminary study of 2-4-8 had limitations inherent in its non-experimental, pilot study design. The sample size was small, which did not allow analyses to control for the number of meetings or other important demographic information (e.g., diagnosis category, academic standing). Future research should further investigate influencing factors that impact success. In addition to the lack of control variables, the outcome measures in this study included a self-report scale that was not psychometrically tested. Future evaluations of 2-4-8 should include psychometrically tested scales of academic skills, in addition to other measures of academic success, including GPA and retention. Collecting outcome measures from multiple courses would allow for triangulation of data collection and would strengthen the validity of responses collected. Finally, this study only evaluated 2-4-8 at one institution. Future research should look to see if these initial findings are replicated at other colleges and universities. These limitations and directions for future research show that more extensive research needs to be conducted on the potential outcomes and benefits of the 2-4-8 model.
As the number of students with disabilities continues to rise, DS offices must provide proactive support instead of relying on reactive support when crises arise. In part, such support is necessary because proactive support decreases load and intensity of future cases. 2-4-8 is a unique proactive advising model that helps all students with disabilities get off to a good start. This study provides a preliminary investigation into academic skills in students with disabilities before and after participation in a 2-4-8. Overall, findings from this study provide promising indications that perception of academic skills, including organization, time management, studying, and professor communication, are increased after participation in 2-4-8. While this is a preliminary and limited study, findings provide promise that 2-4-8 could be an effective means of support for college students with disabilities. This proactive advising model has potential to provide quality, proactive support for many students with disabilities without overburdening DS staff. It is imperative that future research be conducted to expand the understanding of the benefits of this program.

References

Section 504, Rehabilitation Act of 1973, 29 USC §794.
About the Authors

Caitlin Rothwell received her B.S. degree in Psychology from Saint Joseph’s University and M.A. degree in Psychology from the Catholic University of America. She is currently pursuing her Ph.D. in Social Work at the Catholic University of America. Caitlin has both research and clinical experience working with children, young adults, and adults with disabilities. She is currently the Director of the Office of Disability Support Services at the Catholic University of America. Her research interests include evaluation of programs supporting college students with disabilities. She can be reached by email at: rothwellca@cua.edu.

Joseph J. Shields is a Professor Emeritus in the National Catholic School of Social Service at the Catholic University of America where he taught courses in research methodology, statistical methods and social theory for over 40 years. He received his B.A., M.A. and Ph.D. degrees in sociology from Catholic University. His research areas are health services, substance abuse and mental health. He can be reached by email at: shields@cua.edu.
Measuring Inclusive Instruction at German Universities: Extending Validity Evidence

Allison Lombardi¹
Laura Buenner²
Julia Loose²,³
Olaf Hoos²

Abstract

Promoting the use of inclusive instruction based on the tenets of Universal Design has occurred in the United States over the past three decades. In this study, a validated measure of university faculty attitudes toward inclusive instruction was translated from English to German and administered to a sample of faculty at a German institution. Responses (n=589) were subjected to an exploratory and confirmatory factor analysis in order to validate the translated items. The exploratory factor analysis yielded seven factors, which were very similar to the English version of the measure. The confirmatory factor analysis indicated the seven-factor solution showed acceptable model fit. Implications are discussed for universities both in the United States and abroad.

Keywords: higher education, university faculty, attitudes, international, universal design, inclusive instruction

Across the globe in colleges and universities today, undergraduate enrollment is more diverse than ever, and specifically with regard to students with disabilities (National Center for Education Statistics, 2017). As a result, many college faculty now use a variety of inclusive teaching practices to meet the needs of diverse students (Lombardi et al., 2018). For nearly three decades, Universal Design (UD) has been proposed as a conceptual underpinning to inclusive instruction in the context of higher education and disability, and diversity more broadly. Efforts to define and operationalize inclusive instruction grounded in UD, as well as to build faculty awareness of such practices, continue to persist in the literature (e.g., Faggella-Luby et al., 2017; McGuire, 2014). Although some studies focus on measuring inclusive instruction among faculty, very few of these studies are multi-institutional. In fact, lack of scaling-up to multi-institutional research designs remains a major limitation to these types of studies in the U.S.

The purpose of this study was to apply use of a psychometrically valid measure of university faculty inclusive instruction to an international context. Specifically, a larger movement in Germany to promote inclusive instruction offered the opportunity to study faculty attitudes toward disability and teaching practices more closely. As such, a measure that was previously developed in the United States was translated into German and administered to faculty across universities in Bavaria, the southern region in Germany. In this study, we describe the efforts to measure inclusive instruction, including validating the measure in German based on a sample of faculty at one German university, as well as describe some initial findings about inclusive higher education in Germany.

Measuring Inclusive Instruction

In the United States, the concept of Universal Design is well established as an underpinning to university teaching. Arguably, the two most prominent variations of the original framework from the field of Architecture are Universal Design for Instruction (UDI) (McGuire et al., 2003) and Universal Design for Learning (UDL) (Rose et al., 2006). These frame-
works are meant to aid faculty in promoting maximum usability and accessibility in the planning, delivery, and evaluation stages of instruction. Ultimately, the various UD frameworks promote inclusive instructional practices.

**European Context**

By ratifying the United Nations Convention of the Rights of Persons with Disabilities (CRPD) in March 2009, the Federal Republic of Germany committed itself to create an inclusive education system in order to provide people with disabilities equal access to the university system. Within European countries, the number of students with disabilities (SWD) and a resulting student hardship has increased in recent years from 7% to 11% (Middendorff et al., 2013; Middendorf et al., 2017).

The attitudes of university faculty are seen as a key success factor in this regard (Ahmmed et al., 2012; Boyle et al., 2013). The attitude of university faculty toward SWD has a significant impact on students’ academic success (Garrison-Wade, 2012). Negative attitudes and perceptions are the biggest barrier for SWD, such as the frequent use of stereotypes (Baker et al., 2012). Insufficient knowledge and disability awareness (Burgstahler & Moore, 2009) may lead to prejudices and negative attitudes among faculty toward SWD, which may, in turn, negatively impact SWD experiences in college courses.

A lack of faculty awareness of disability sometimes even results in the questioning of the impairment (Leake & Stodden, 2014). This mainly affects students with non-visible impairments, who comprise as much as 94% of the SWD population in Germany (German Student Information, 2013), and who report among others about the lack of acceptance for needed accommodations. In general, it is difficult for college faculty to determine appropriate accommodations (Vogel et al., 2008), so that only easy-to-implement adjustments are granted (Becker & Palladino, 2016). “Inadequate” also describes the level of knowledge of the teachers with regard to legal requirements in the interests of those affected students (Moriña, 2017). Faculty also may not be familiar with the different types of disabilities (Vogel et al., 2008), and disability support services offered by the university are quite varied across institutions (Burgstahler & Moore, 2009).

Furthermore, there seem to be differences in disability awareness among faculty that may depend on their respective disciplines. For example, faculty from the humanities and economics fields are not as aware of inclusive instruction than faculty from colleges of education specifically (Becker & Palladino, 2016).

Typically, university faculty are not trained in inclusive instruction (Faggella-Luby et al, 2017; Lombardi et al., 2018). A thematic training would be necessary to bring about changes in attitudes and thus in the behavior of the faculty, which, in turn, may have a positive effect on the interaction of these with the SWD (Zhang et al., 2010). In order to design such training opportunities, it is first important to reliably and validly measure faculty attitudes and perceptions toward disability and inclusive instruction. As such, the purpose of the current study was to validate a translated measure of faculty inclusive instruction in order to reliably and validly use at German universities.

**Method**

**Sample**

The sample was composed of 589 faculty (response rate was approximately 21%) at one university. Most of the respondents were teaching at the Julius-Maximilians University Würzburg. Over half (60%) of the participants were male; most were under 51 years old (<35J: 42.4%, 36-50y: 34.8%, 51-65y: 22.2%, > 65y: 0.5%) and had been teaching for 10 years or more (41.1%). There were 58.4% of the respondents who were employed on a temporary basis, mainly as scientific staff (52.5%). This sample is considered representative, although there is an over-representation of the humanities and catholic theology as well as an underrepresentation of medicine. With 63.1%, the courses of the respondents are listed as compulsory subjects for undergraduate students (45%).

**Measure**

A validated measure of inclusive instruction, the Excel questionnaire (Lombardi et al., 2011) was used in the current study. The instrument consists of three sections. First, demographic data were collected; second, the use of topic-specific training was addressed; and third, 39 items were used to analyze the attitudes and perceptions of faculty members towards SWD. The 39-item Excel survey measures attitudes toward accommodations, disability-specific laws and inclusive instruction, and is based on eight factors that account for 60% of the variance. Cronbach’s alpha of all items is 0.88 (Lombardi et al., 2011). More recently, the measure was further developed and refined and renamed into the Inclusive Teaching Strategies Inventory (ITSI) (Lombardi et al., 2011). Consistent with previous versions, a six-point Likert response scale was used, ranging from 1 = “strongly agree” to 6 = “strongly disagree.”
German translation. The instrument was translated into German using the technique of Banville et al. (2000). The items were adapted after a back and forth translation of the German usage and the Bavarian university system.

In the demographic part, “diverse” was added as the third choice for gender, while the answers to the employment relationship were reduced to “permanent” and “temporary.” The open questions about age and duration of employment as a teacher have been converted into closed questions. The area of further education was also revised and supplemented with further training topics that could be of interest to teachers according to previous studies. Furthermore, in the original questionnaire, a question asked about training, including further education and self-taught further education. This subdivision was taken up in the German version in two separate issues.

The third set of items was subject to validation, which was the purpose of the current study. With regard to translation, items that referred to laws were changed in accordance with the European Union and German context. In addition, the sequence of the items, which had previously been designed according to factors, was arranged randomly. As such, a major goal of the current study was to determine whether the original factor structure could be confirmed in the Bavarian context and translated into German.

Procedures

Prior to the large sample data collection, the translated items underwent a pilot phase. The pilot study was attended by 23 instructors from different disciplines of one university. Furthermore, the items were presented to experienced university staff from the field of empirical educational research. Corresponding to the results, a few linguistic changes and ambiguous terminology were clarified for better comprehensibility. In particular, the term “disability” was addressed in remarks by pilot test respondents. It was difficult to come to an agreement on one term that encompassed the diverse array of disability types. This problem was also reflected in a related qualitative study, where in one-on-one interviews, instructors synonymously referred to the term “disability,” “impairment” or, for example, also “handicap” (Hoos et al., 2020). In addition, disorders such as dyscalculia or dyslexia were often referred to as “learning disability/impairment.” Therefore, to encompass all disability types, the foreword to the questionnaire stated that SWD refers to students with physical, mental, and chronic disabilities as well as learning disabilities.

After the pilot phase, the revised measure was administered using the online provider SoSci Survey, which was free of charge for scientific researchers who collected the data. To participate, instructors were invited by email, sent on behalf of the respective disability officer and the university management. Standardized text was made available to the universities for the invitation emails and the reminder email.

Data Analysis

The pilot phase was conducted with 23 participants. In the validation phase (n=589), an exploratory factor analysis (EFA) and a confirmatory factor analysis (CFA) was conducted. All analyses were conducted with SPSS Statistics 25 and R (3.3.3). With regard to data selection, all cases with missing data from 30% and from 30% missing values in the last part (39 items) were excluded from the analysis (Graham, 2012). Missing values of the variables were replaced by averages because on average only 2% (Range: 0% -12%) of the information was missing (Little & Rubin, 2002).

For the EFA, the purpose is to reduce items through a smaller number of factors. The extent to which data was suitable for a factor analysis was given by the Kaiser-Meyer-Olkin Criterion (KMO), which should assume a value above .5 (Cureton & Agostino, 1983). The extraction took place via the KMO criterion, the examination of the Scree plot and a parallel analysis. To ensure optimal consistency and stability of the factor structure, various rotation methods (Varimax, Oblimin, and Maximum Likelihood) were compared. The original study used the Oblimin (0.4) rotation method (Lombardi & Murray, 2011). Items that were ambiguously loaded on different factors and with loadings under .3 were excluded.

The resulting model was compared to the original model by means of a confirmatory factor analysis (CFA), which is typically used to study the nature and relationship of latent variables (Jackson et al., 2009). To assess the global quality and acceptance of the model, standard indexes were considered for CFA (Hu & Bentler, 1999). These include the smallest possible chi square to degrees of freedom ratio, or \( \chi^2/df \), with a value between 2 and 5 (Seifried & Heyl, 2016). Furthermore, the following indices with corresponding cut-off values were accepted as suitable measures for considering the global quality: Comparative Fit Index (CFI) of .90 or higher, Root Mean Square Error of Approximation (RMSEA) and Standardized Root Mean Square Residual (SRMR), both of which should be .08 or lower, as well as the Akaike Information Criterion (AIC) and Consistent Akaike Information Criterion (CAIC) with the lowest possible values (Browne & Cudeck, 1992; Hu & Bentler, 1999, Seifried & Heyl, 2016). To check the measure-
Cronbach’s alpha was calculated for the factors and for all items in the inter-item correlations (.30; Bortz & Döring, 2002) and the corrected item scale correlations (.30; Blanz, 2015). In terms of discriminant validity, the factorial delays and the variance extracted per factor were calculated (Seifried & Heyl, 2016).

Results

With SWD, most instructors have had contact (63.5%) in teaching during the past five years, with 50.7% specifying this to be 1-5 SWD. Nevertheless, 41.9% of the participants stated that they had not yet had any personal experience with the topic of disability. Almost the same number (42.5%) said they already had experience with family members, friends, or personal contacts. Further, 18.3% of respondents had experience teaching SWD and 4.8% reported having an impairment themselves.

The second set of items pertained to interest in further training on specific disability-related topics. Results showed that instructors were particularly interested in the topic of mental illness, while other specific types of disabilities were ranked lower. In addition, 9% of the participants had already attended subject-specific training, most of them (35%) continued between 4 and 6 hours. A quarter of all faculty learned about the topic mainly through websites (77%), investing between one and three hours of their time.

With regard to the EFA results, according to the KMO criterion, the extraction provided nine factors. However, two were only slightly above 1 (eigenvalue F9: 1.07, eigenvalue F8: 1.09), and therefore all methods were also performed with preset 7, 8 and 9 fixed factors. The Scree plot and parallel test indicated seven factors. The strongest factor loadings were found by the Oblimin method (0; 4), so that was used for further analysis. In addition, this rotation method was also used in the original study. Here, with 59.7% of variance explained the factor structure could be considered reproducible. However, factors eight and nine showed latent features that were not interpretable because each had only two items. In addition, individual factorial reliability proved to be insufficient, which resulted in a factor structure of seven reproducible factors, loading at least with three items (charge at three items over .5) and showing a reliability between, in a case .60, otherwise .68 and .89. The explained variance per factor was between .5 and .66. All items from the 8th and 9th factors were redistributed in the seven-factor solution, except for item 15 (“I prefer the use of different teaching methods, including work in small groups and hands-on activities.”), which did not cross-load on another factor and was therefore eliminated. In the seven-factor solution, 54.1% of the total variance was explained and all remaining variables showed a Cronbach’s alpha of .91. The values of the corrected item scale correlation were occasionally at .3, but mostly between .5 and .79 and therefore adequate. On average, the inter-item correlation was above .3, except for one factor which also showed the lowest reliability. Based on this structure, the determined factors were: (a) support for accommodations, (b) knowledge of disability, (c) willingness to invest time to learn about inclusive instruction, (d) accessibility of (course) materials, (e) performance expectations, (f) support services and, (g) willingness to adjust to course performance and requirements. Importantly, these factors were quite similar to the original factors in the English version of the Excel survey (Lombardi & Murray, 2011).

Table 1 shows descriptive statistics and reliability by factor for both the original English version and the translated German version of the instrument. As shown in the table, the factor names were closely translated in the German version, although some were not exact translations. Table 2 shows the CFA results, of which all reported fit indices show acceptable to good model fit (Browne & Cudeck, 1992; Hu & Bentler, 1999) for all seven-, eight- and nine-factor solutions, with the seven-factor model showing the best model fit.

Discussion

In this study, we examined the psychometric properties of a translated version of the Excel survey, a measure of university faculty attitudes toward inclusive instruction. The Excel survey was previously validated in English (Lombardi & Murray, 2011) and has since been revised several times and used at various universities in the United States and abroad (Lombardi, Murray, & Dallas, 2013; Lombardi et al., 2011; Lombardi et al., 2015). The results of this study are particularly noteworthy because it is the first examination of the Excel survey in German. Results show that the translated instrument is reliable and valid and should be used with confidence in German-speaking contexts.

The Excel survey, which was later renamed the Inclusive Teaching Strategies Inventory (ITSI), is an important component of data-based decision making. Disability services providers can use the instrument to gain a better sense for gaps of knowledge in faculty on their campus. This type of data is valuable for faculty training and outreach efforts. There are numerous examples of such previous efforts in the
### Table 1

**Descriptive Statistics and Reliability for English and German versions of the Excel Survey**

<table>
<thead>
<tr>
<th>Factor (English)</th>
<th>Factor (German)</th>
<th>English</th>
<th></th>
<th></th>
<th>German</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>α</td>
<td>X</td>
<td>σ</td>
<td>α</td>
<td>X</td>
<td>σ</td>
</tr>
<tr>
<td>Fairness in the provision of accommodations</td>
<td>Support for accommodations for SWD</td>
<td>.85</td>
<td>5.09</td>
<td>.63</td>
<td>.89</td>
<td>4.71</td>
<td>.72</td>
</tr>
<tr>
<td>Knowledge in the context of disability</td>
<td>&quot;…”</td>
<td>.82</td>
<td>3.30</td>
<td>1.08</td>
<td>.86</td>
<td>2.92</td>
<td>1.09</td>
</tr>
<tr>
<td>Willingness to invest time</td>
<td>Willingness to invest time to learn about inclusive teaching</td>
<td>.74</td>
<td>4.75</td>
<td>.83</td>
<td>.70</td>
<td>3.78</td>
<td>.99</td>
</tr>
<tr>
<td>Accessibility of course-materials</td>
<td>&quot;…”</td>
<td>.69</td>
<td>4.81</td>
<td>.79</td>
<td>.77</td>
<td>4.87</td>
<td>.88</td>
</tr>
<tr>
<td>Performance expectations</td>
<td>&quot;…”</td>
<td>.65</td>
<td>4.96</td>
<td>.63</td>
<td>.60</td>
<td>4.72</td>
<td>.73</td>
</tr>
<tr>
<td>Campus resources</td>
<td>Support services</td>
<td>.69</td>
<td>4.24</td>
<td>.82</td>
<td>.68</td>
<td>3.79</td>
<td>.90</td>
</tr>
<tr>
<td>Adjustments to course and performance requirements</td>
<td>willingness to adjust to course and performance requirements</td>
<td>.78</td>
<td>3.86</td>
<td>.85</td>
<td>.75</td>
<td>4.67</td>
<td>.80</td>
</tr>
<tr>
<td>Minimizing barriers</td>
<td>-</td>
<td>.70</td>
<td>4.29</td>
<td>.94</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

### Table 2

**Confirmatory Factor Analysis Results**

<table>
<thead>
<tr>
<th></th>
<th>$\chi^2/df$</th>
<th>CFI</th>
<th>RMSEA</th>
<th>SRMR</th>
<th>AIC</th>
<th>CAIC</th>
</tr>
</thead>
<tbody>
<tr>
<td>original model</td>
<td>2.9</td>
<td>.83</td>
<td>.063</td>
<td>.075</td>
<td>2179.497</td>
<td>-2868.682</td>
</tr>
<tr>
<td>modified model, 9 factors</td>
<td>2.8</td>
<td>.84</td>
<td>.061</td>
<td>.068</td>
<td>2113.864</td>
<td>-2908.323</td>
</tr>
<tr>
<td>modified model, 8 factors</td>
<td>2.9</td>
<td>.83</td>
<td>.063</td>
<td>.070</td>
<td>2083.986</td>
<td>-2709.445</td>
</tr>
<tr>
<td>modified model, 7 factors</td>
<td>2.8</td>
<td>.84</td>
<td>.062</td>
<td>.068</td>
<td>1932.948</td>
<td>-2633.727</td>
</tr>
</tbody>
</table>

*Note. $\chi^2/df$: Chi-square value to degrees of freedom ratio; CFI: Comparative Fit Index; RMSEA: Root Mean Square Error of approximation; SRMR: Standardized Root Mean Square Residual; AIC: Akaike information criterion; CAIC: Consistent Akaike Information Criterion.*
United States, such as recent findings that show faculty attitudes towards adopting inclusive instruction can improve after receiving disability-related training (Lombardi & Murray, 2011; Lombardi et al., 2011; Murray et al., 2009; Murray, et al. 2014; Murray et al., 2010). Unfortunately, despite the promise of these findings, higher education institutions continue to report barriers of universal design implementation due to limited staff resources and minimal faculty interest (Raue & Lewis, 2011). Moreover, when faculty positively endorse aspects of inclusive instruction, these same faculty might not be implementing such practices (Cook et al., 2009; Lombardi, Murray, & Gerdes, 2011; Zhang et al., 2010). These findings suggest that faculty may understand the importance of inclusive instruction, yet may lack the time and resources to adopt such practices, which may affect their interest.

Previously, one study examined inclusive instruction among college faculty on an international scale, focusing on comparisons between the United States, Canada, and Spain (Lombardi, et al., 2015). In the current study, German faculty comprised the sample and only attitudes (not actions) were the focus of measurement. Yet, this study is the first to illustrate a snapshot of such attitudes among German faculty, and also provides further validity evidence for the instrument after translating the items. With a psychometrically valid instrument, German universities may consider surveying faculty to make data-based decisions on training opportunities and topics to be prioritized and provided in the future. Importantly, there are now effective Spanish and German translations of this measure.

The current study shows the language of inclusive instruction can be effectively translated into German. As previously mentioned, this current validity study was part of a larger effort to promote inclusive instruction at five universities in the southern German region of Bavaria. After validating the survey in German, data were collected at other German universities for this purpose. An important next step will be for German researchers and higher education administrators to translate resources that support facilitation of inclusive instruction beyond the Excel survey. With regard to faculty training opportunities, Lombardi et al. (2018) describe four specific teaching tools that promote inclusive instruction, which address syllabus design, course mapping, lecture, and assessment. Resources like these should be translated into German to further promote inclusive instruction.

Ultimately, SWD in higher education are increasing in the United States and abroad. As such, promoting inclusive instruction among college faculty is a critical global need. Surveying faculty about their teaching practices is an important first step to identify gaps in knowledge and to prioritize future trainings. The current study shows the Excel survey items function similarly in English and German, and as such, German universities should feel confident in using the survey.

References


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### About the Authors

Allison Lombardi received her M.A. degree in Education from the University of California, Berkeley, and Ph.D. from the University of Oregon. She is currently an associate professor in the Department of Educational Psychology at the University of Connecticut. Her research interests include college and career readiness for students with disabilities and promoting inclusive instruction among university faculty. She can be reached by email at: allison.lombardi@uconn.edu.

Julia Loose received her B.A. and M.A. degree in Special Education from Julius-Maximilians-University in Wuerzburg, Germany. She is currently a PhD-student at the Leibniz Center for Science in Society in Hanover. Her research interests include inclusion in higher education and student-faculty interaction. She can be reached by email at: julia.loose@lcss.uni-hannover.de.

Olaf Hoos received his state diploma for teacher education and his Ph.D. in sport and exercise science from University of Marburg, Germany. His experience includes working as a professor for physical education teacher education and serving as a commissioner for students with disabilities and chronic illnesses at the University of Wuerzburg. He is currently a professor in the Department of Sport and Physical Education of the Faculty of Human Sciences at the University of Wuerzburg. His research interests include social inclusion in higher education and Adapted Physical Activity. He can be reached by email at: olaf.hoos@uni-wuerzburg.de.
Animals on Campus:  
A Look at HUD’s Advised Process and Student Outcomes  
(Practice Brief)

Lauren E. Poindexter¹  
James C. Marconi²

Abstract

This study examined one Midwestern university’s emotional support animal (ESA) population and asked the question, “Are ESAs effective in the context of higher education given the academic and social demands of a student?” The number of ESA requests has increased in recent years as more students considered an ESA to help regulate emotions. This study began as a means to review our process and measure student outcomes with data gathered by surveys sent to 122 current and former students with an ESA. The survey utilized a five-point Likert Scale and open-ended questions to gather responses. Twenty-one students started the survey with 18 completing it. The survey was designed with questions that measured participants’ academic experience, interpersonal skills, intrapersonal skills, and mental health, in addition to open-ended questions related to these four key areas. The results of the survey were largely positive in the four key areas. This university utilized an ESA request process advised by Housing and Urban Development.

Keywords: emotional support animal, ESA, higher education, mental health, student experience

Emotional support animals (ESAs) are part of a larger category of animals that take on assistive, therapeutic, and emotional support roles. Parenti et al. (2013) identifies several characteristics that distinguish categories of assistance animals. If the animal performs tasks related to an individual’s disability, it is a service animal. If the animal is used by public service, military, or healthcare professionals, it is a public service animal. Animals with training certifications or standards, where available, are typically types of therapy animals or visitation animals, while an emotional support animal is more specifically defined as, an animal that provides emotional support that alleviates one or more identified effects of a person’s disability (Housing and Urban Development, 2008). Applied to higher education, ESAs are only permitted to occupy residential spaces and cannot enter classrooms and campus facilities unless the handler has specific accommodations. While Title II and Title III of the Americans with Disabilities Act (n.d.) allows service animals to enter all facilities on a campus with their handlers, people who rely on ESAs are not afforded such protections.

In their 2019 article, Chandler references three separate events, each covered by a major news outlet, in which an emotional support animal caused injury to a human or service dog. In one of the cases, a dog that the owner claimed to be an ESA, but later admitted was not, caused an incident with a service dog in an elevator. Chandler used this case to highlight the fact that dogs may bite, especially untrained dogs. In another recent incident, a New Jersey resident’s service dog, Beauty, was attacked by two unrestrained dogs in a mall (Deminski, 2020). The owner of the dogs claimed they were ESAs. In their opinion article, Deminski had harsh words for ESA owners who bring their animals into public places. The one point highlighted by this incident is the disservice that occurs to people with disabilities when ESAs are treated as something they are not, and when the owners of ESAs do not comply with laws.

Chandler (2019), who is in favor of ESAs in the owner’s residence, highlighted the dubious documentation of “commercial enterprises that take money from the pet’s owners” for a worthless registration or certificate. The author notes three questionable
activities based in the ethics of mental health care. First, the questionable ability to thoroughly assess the actual need for such an animal based on a singular visit. Second, the consideration of a client’s ability to determine whether or not an ESA would be detrimental to others or property. Third, the extent to which some mental health care providers supply documentation for individuals with whom they have had little to no contact.

In their 2015 study, VonBergen found that students with disabilities have increasingly petitioned colleges with no-pet policies to permit them to bring their animals to campus. Students in this study were found to have asserted a need for a companion or emotional support animal to make college life easier and to reduce their stress, loneliness, depression, and/or anxiety. With the increase measured by VonBergen, it was likely that more universities would experience growth in ESA requests. A survey of the professional listserv of the Association of Higher Education and Disability (AHEAD) from January 1, 2020 to February 29, 2020 listed twenty individual topics spanning multiple days of discussion of ESAs. This brief survey of topics showed there were still frequent questions relating to documentation and current practices.

The increased interest in ESAs may be due to the role that companion animals can play in supporting people of all ages. Risley-Curtiss (2010) documented the success of the human and companion animal bond with children and adults in feeling a sense of security and unconditional love, contributing to a child’s cognitive and language development, and contributing to an elderly person’s ability to carry out daily activities. While the human and companion animal bond may create certain favorable mental health outcomes, not all companion animals are necessarily ESAs.

In a synthesis of 17 studies related to benefits of animal ownership, Brooks et al. (2018) found three common themes: emotional work (symptom mitigation), practical work (symptom distraction and physical activity), and biographical work (identity and existential meaning). Qualitative data largely showed animals were able to provide unique support to their owners in all three themes. However, quantitative data were mixed. Quantitative data in emotional work mostly showed neutral or small negative impacts for owners while quantitative data from the studies on practical and biographical work associated with mental health management pointed to the positive impact of dog ownership specifically.

Psychologists, social workers, and veterinarians point to the same literature documenting the often-positive impact of animals on mental health and wellbeing (Fine et al., 2019; Risley-Curtiss, 2010; Younggren et al., 2016). While support for emotional support animals as a treatment is not in question, research detailing the impact on students and higher education is still limited. This fact is further complicated due to the way certifications are issued and the qualifications and appropriate training regarding recommending or prescribing an animal as a treatment are likely limited.

Clinical psychologists, or treating psychologists, are often called upon to provide administrative services, like emotional support animal evaluations, to their patients given the close nature of the relationship. However, Younggren et al. (2016) highlight this as an ethical concern. Clinical psychologists make treatment plans based solely on the subjective history presented by the patient introducing potential bias and inaccuracy in a diagnosis. The authors argued that forensic psychologists should be the professionals making ESA evaluations and anything else constitutes a role conflict. Boness et al. (2017) consider ESA evaluations a forensic activity that should not be conducted by treating mental health practitioners. However, their survey results demonstrated how treating and forensic practitioners fail to understand that this is a forensic activity, resulting in less than thorough evaluations and major ethical concerns. When considering animal-based treatment interventions in general, Taylor et al. (2016) argue that the ethical legitimacy of animal assisted therapy rests on the willingness to understand animals as sentient beings with needs of their own, not just possessions or tools for humans to use. Whether being used as tools, or conversely being underutilized, Risley-Curtiss (2010) suggests that speciesism plays a significant role and that all stakeholders should be mindful of the place of animals in a treatment capacity.

Despite the recommendation for forensic specialists in evaluating the need for ESAs, social workers are the likely professionals to work with individuals and families with companion animals; thus, the inclusion of such animals in both practice and research as a natural extension of social work with humans, and their challenges, coping mechanisms, and resiliency factors, is valid (Risley-Curtiss, 2010). Risley-Curtiss found that social work practitioners have basic knowledge of the negative and positive relationships between humans and companion animals. Fewer than 25 percent of social workers included companion and other animals in their intervention practices, although the majority have had no special training or coursework to do so. The assumption is that this favorable view extends to recommending ESAs as interventions. Taylor et al. (2016) noted that social work is oriented towards caring for people but does not officially recognize (nonhuman) animals.
Fine et al. (2019) suggested in those situations when a person intends to obtain an animal to be an ESA, a veterinarian should assist with ensuring the animal is suitable for the role and will not experience impaired health or welfare as a result. Currently, no formal federal policies require that a veterinarian evaluate the suitability of an ESA, although airlines may request documentation from a veterinarian regarding the animal’s current health status (U.S. Department of Transportation, 2020). Fine et al. (2019) noted when assisting an individual in acquiring an ESA, the veterinarian should have specific knowledge of the species the owner is requesting, because certain species may not be suitable in certain situations or may become distressed in public spaces. Active teamwork between clients, veterinarians, and human health-care professionals could ensure that more benefits are experienced by people and their animals. However, this measure could potentially lead to the problem of creating undue burden if a student must consult with their care provider, a veterinarian, the disability office, and residence life.

Emotional support animal users may just need interaction when experiencing stress, while other users may seek this interaction on a daily basis as a way to enhance their quality of life (Risley-Curtiss, 2010). Historically, emotional support animals were referred to as companion animals. However, the distinction between a companion animal and an emotional support animal is the ability to provide psychological benefits to the owner without formal training to do so.

**Depiction of the Problem**

Disability Services at the institution in the present study was reviewing its process for determining eligibility for ESAs in campus housing by examining the steps and documentation students must complete for the university’s consideration of accommodation. Looking at the office’s own history, it was apparent that a steady and significant increase year after year necessitated a review. Through the review of the notable increase in ESA requests and approvals, two main problems, or questions, arose: (a) What are the effects ESAs have on the life of a student on campus?, and (b) How should disability services staff make sense of documentation presented by the student given the vast number of dubious animal certifications (i.e., Who should be considered qualified to complete the verification forms?). Given the legal ambiguity and limitations from Housing and Urban Development (HUD) when they resolve a campus housing complaint, this is more of an ethical or access question, rather than a legal question regarding the request and approval process.

**Participant Demographics and Institutional Partners/Resources**

The survey was conducted at a large primarily residential Midwestern university. The survey was emailed to 122 current and former students who either in the past or at the time of the survey lived with an ESA in campus housing. Respondents were gathered from an internal system used to track ESA requests and approvals. Data have been kept internally since fall of 2013. Utilizing the information from this list of requests, a provisional respondent list was created. Because tracking has changed slightly since the inception of this list, the list was filtered to remove duplicate names and requests that were left “in process” due to students never submitting all necessary requirements. The filtered list left 122 current and former students.

The students were emailed a Qualtrics link to the anonymous survey that remained open from February 4 to April 1 with a follow up email sent on February 28, 2020. The survey concluded with 18 recorded responses (14.75% response rate). Three additional surveys were started but left incomplete; these were excluded from the results and the response rate.

**Description of Practice**

Under guidance from the University’s Office of the General Counsel and lawyers from Housing and Urban Development, the ESA request process was changed from its prior iteration that relied on more questions and an interactive process with the students to one that could only require some sort of documentation of a disability and two questions answered by a treating professional: (a) Does the individual have a disability?, and (b) Does or would the assistance animal provide some type of disability-related assistance to the individual? While emotional support animals have existed on campus for years prior, the increase in requests and the limiting of the interactive process raised questions regarding ESAs at the University. The process begins with Disability Services and the authorized questions and supporting documentation. Once approved, the student and Housing and Residence Life are notified to sign the housing contract and fulfill the accommodation.

This process revision prompted questions regarding the overall outcomes of students who currently, or previously, received an ESA accommodation. The documentation requirements and process revisions were substantial, but the data gathered from the survey that followed the process change were more enlightening than a simplification of process could have
been. While both were innovative on their own, it was the unity and timing of both the process revision and structured inquiry that created a system for understanding the phenomenon. An overburdened process can restrict access and provide accommodations without follow-up data on the success of students, which would provide no opportunity to understand the impacts on students. These two practices, one that occurred at a single point in time, and the other, an ongoing data collection, will provide meaningful data as Disability Services, Housing, and the University navigate the question of ESAs, moving forward.

The survey measured participants’ academic experience, interpersonal skills, intrapersonal skills, and mental health through a five-point Likert scale in addition to open-ended questions. In the latter section participants were asked the following:

- What impact has your ESA had on your overall experience at the University?
- If you registered for an ESA with Disability Services but did not bring the ESA back to campus please explain why.
- Please share how your college experience differed when you had the ESA compared to any time in college you did not have the ESA.

**Evaluation of Observed Outcomes**

Results from the ESA survey do show an increase in the four key areas: academic experience, interpersonal skills, intrapersonal skills, and mental health. Each of these four areas contained a subset of five criteria being measured. The survey was sent to participants at the beginning of the Spring 2020 semester, prior to the nationwide outbreak of COVID-19. The researchers believe the response rate was limited due to this fact. Additionally, the ESA request and approval numbers were stopped in mid-March due to the campus transitioning to remote learning. The majority of responses expressed a positive subjective outlook on academic integration while a slight percentage expressed a negative impact on social interactions.

For the theme of Academic Experience, the results were largely positive, with only the subset of co-curricular activities and educational activities being slightly negative. “Degree Completion” and “Academic Achievement” were rated highly by participants, both with 77.78% of the subset responses.

Interpersonal Skills were rated favorably in the somewhat positive and extremely positive categories, but compared to the other skills measured in the survey, interpersonal skills accumulated the most somewhat negative and extremely negative responses. While this section held more negative responses there were no cumulative negative response rates higher than 11.11%, or two responses, in the “Belonging on Campus” subset.

Both the Intrapersonal Skills and Mental Health categories received far more responses marked as extremely positive and received no responses marked as somewhat negative or extremely negative. While most results related to the Mental Health category were extremely positive, the effect of ESAs on attention span, memory, problem-solving, and decision making was noticeably lower than the other categories measured. This indicated that while there was some improvement, ESAs were less effective in these specific measurements. The largest single response in the survey came from the Mental Health section. The most responses (83.33%) of any question came from the extremely positive response measured when asked about the effect of ESAs on developing healthy coping mechanisms.

Intrapersonal Skills questions were designed to evaluate confidence, values and morals, independent thinking, intuition, and level of self-reflection. The largest categorical response rate (77.78%) related to the effect of ESAs on values and morals. The written responses did not explicitly indicate why the values and moral category scored higher than the others, but the responses about caring for an animal could be some indication. This survey was not designed to measure this category explicitly, so no conclusion could be drawn without further research.

Students’ written response portion highlighted their ESA experience. The students noted how their ESA helped them to “be more confident and branch out socially,” “connect with people socially…she helps me get out and talk to people,” and “daily life motivation.” One student with self-harm and suicidal ideation found that with therapy and their ESA they have “been able to cope.” One student even said, “It made me feel more comfortable with being at the University and being able to call it my home.”

**Implication and Portability**

The results of the students surveyed appear to suggest that the growth and continued access granted by an ESA have some positive impacts on student well-being and degree completion. The approach used by our University in terms of required documentation and who is considered a treating professional appears to be a less heavy-handed approach than some others. This approach seems not to create additional steps in the process which might later be found excessive or restrictive. While the authors think there should be a smooth approval process that requires
documentation, the positive effects of possessing an ESA appear to outweigh the possible downsides of the scant approval process directed by Housing and Urban Development.

Our survey was designed to gain a better understanding of the effect of ESAs while contemplating our own revised approval process. If the results of the survey were merely neutral with no clear benefits or revealed negative effects, then our simple ESA request process would have been called into question for allowing potentially detrimental influences on campus with unnecessary ease. However, our survey showed positive results in all categories. The revised process helped to remove administrative barriers on its own, but in conjunction with the survey, Disability Services was able to gain a better understanding of the positive impact ESAs had on students. The simplified process and the survey demonstrated a practice that has future portability for our office as it will allow us to measure not only the number of individual requests, but also the effectiveness of the accommodation. Students are required to start the process in Disability Services, but once they have been approved, they discuss the ESA and the housing contract with Housing and Residence Life. There are no breed or size restrictions but if there are safety concerns requests can be denied. This is consistent with VonBergen’s (2015) research, which showed how animal accommodation requests may be denied if the animal in question poses a direct threat to the health or safety of others, and is one that cannot be reduced or eliminated by other reasonable accommodations. Additionally, institutions should be mindful that extra restrictions (breed, size, weight) and conditions (deposits, pet rent, etc.) cannot be placed on emotional support animals.

While the researchers were not able to analyze meaningful longitudinal data for retention and graduation for students with ESAs in this survey, it provided Disability Services with meaningful data on the student experience, retention considerations related to emotional support animals, and a more specific measurement than an annual disability climate survey. Implementing this practice in conjunction with a revision of the ESA accommodation process has created a system of greater understanding of the impacts animals play in the emotional wellbeing and success of students. Both the revised process and the survey created a new perspective when viewing the rise of ESA requests. The student responses indicated there was a positive effect on mental health, academic achievement, and progress towards degree completion. While ESAs follow a different approval process than test accommodations and even single room requests, the student responses show they have been integral to meaningful college progress.

References


About the Authors

James Marconi received his B.A. degree in Religious Studies from Indiana University Purdue University Indianapolis, a MALS in Theology from Valparaiso University, and an M.A. in Student Affairs Administration in Higher Education from Ball State University. His experience includes working in Student Affairs at Valparaiso University and most recently as Assistant Director of Disability Services for Ball State University. He is currently leading Human Resources for a regional accounting firm. His research interests include the construction of meaning, values, and student success. He can be reached by email at: jmarconi@bsu.edu.

Lauren Poindexter received her B.S. degree from Cornell University and M.A. in student affairs administration from Ball State University. Her experience includes working as a student life counselor for the Indiana Academy for Science, Mathematics, and Humanities and serving as a member of the NASPA Graduate Assistant Program. She is currently a program coordinator in the Department of Student Affairs. Her research interests include belonging and adjustment in first semester students with minoritized identities. She can be reached by email at: lauren.poindexter@utah.edu.
Being Heumann: An Unrepentant Memoir of a Disability Rights Activist  
(Book Review)


Reviewed by Karly Ball

“I never wished I didn’t have a disability” (p. xi). In her book, Being Heumann: An Unrepentant Memoir of a Disability Rights Activist, Judy Heumann challenges readers to envision a reality where disability is not stigmatized. Heumann is an internationally recognized disability rights leader, most recently known for her key role in the 2020 award-winning documentary, Crip Camp: A Disability Revolution. Drawing from her many experiences, Heumann offers insight into the need for a society where disabled people fully belong. Through her story, Heumann offers a mechanism for readers to better understand disability from a disabled person’s perspective. Her recollection of first-hand experiences as a disabled Jewish woman and advocate helps her to inspire positive change, both within higher education and broader social contexts.

Being Heumann is delivered across 12 chapters, divided into 3 parts. Part 1 grounds Heumann’s memoir in her formative experiences as a disabled student and teacher in New York City schools as a way to ground the basis for her advocacy. Part 2 discusses her experiences as a disability rights advocate across the country, offering readers a glimpse into how disability advocacy has historically operated. Finally, Part 3 transitions from her grassroots advocacy to considering Heumann’s leadership roles at both the national and international levels. This part of the memoir gives readers an understanding of how to advocate for disability rights from within positions of power and influence. She ends by bringing her experiences together to form a call to action for future disability advocacy. Part 1 was especially compelling for higher education practitioners who want to understand how institutional practices and policies impact identity development for disabled students. Parts 2 and 3 are helpful for thinking about how to mobilize disability advocates and inspire government-level change, though Heumann’s language felt inconsistent at times.

In Part 1, “Brooklyn, New York, 1953,” Heumann orient readers by presenting her positionality, historical context, and the tension between social and medical conceptions of disability. In these early chapters, Heumann refutes a medical understanding of disability where “if we just ‘fixed’ it, [disabled people] would be fine” (p. 42). Instead, she describes how “we [students] were beginning to see our lack of access as a problem with society” (p. 42). By emphasizing society’s role in limiting disabled people, Heumann successfully “crips” the way readers understand her story. Within student development contexts, “cripping” serves to “expose theoretical discourses that privilege able bodies and minds, pushing students toward an idealized normal” (Abes, 2019, p. 66). By delivering her narrative through acripped lens, Heumann positions readers to understand disabled student development through structural forces that oppress disabled people.

Language also plays a role in how Heumann crips readers’ understanding of disability. Throughout the book, she uses person-first and identity-first language interchangeably. This variation can serve to remind readers that lived experiences do not always fit within clear disability models or categories. Rather, Heumann’s varied use of person-first and identity-first language suggests that the way people identify with disability can vary temporally and across different contexts. Still, Heumann is clear that oppressive and inaccessible systems define her relationship with disability. This understanding informs her disability rights advocacy. For this reason, this review uses identity-first language throughout.

Part 1 is meant to portray Heumann’s development over her entire life, not just as a college student. This scope offers advantages for practitioners trying to understand disabled college student identity development. As recent literature notes, focusing too narrowly on development that occurs within the college context, “misses an important link to understanding how students’ past experiences affect their sense of self, as well as how sociohistorical influences laden with power do the same” (Abes, 2019, p. 153). Heu-
mann’s focus on overall development, as opposed to development that takes place during college alone, offers a way for practitioners to understand college student development as one interconnected piece of a person’s life. This understanding can inform policies and practices that address disabled students’ holistic needs within higher education.

In Part 2, “Berkeley, California, 1977,” Heumann transitions from focusing on development to addressing how “being ignored puts you in the position of having to choose between making a fuss or accepting the silent treatment” (p. 143). She builds on the idea that disabled people are uniquely prepared to negotiate with the people in power they depend on. In these chapters, Heumann shows how disability-related character traits can be used as strengths. For example, she discusses attributes like fluency in sign language as a “secret weapon” used to bolster the disability movement’s advocacy efforts (p. 112). In this sense, Heumann is able to highlight some of the meaningful ways that disabled people can contribute to society.

Heumann’s focus on positive disability-centered attributes is consistent with the idea of background specific strengths (BSS). BSS “refer to the unique knowledge, skills, and perspectives that are acquired as a result of... marginalized backgrounds and associated experiences” (Hernandez et al., 2021, p. 1). Indeed, Heumann illustrates how disability-specific BSS uniquely position disabled people “to do whatever you can to get their [government officials’] attention” (p. 133). Heumann applies this idea to the disability rights movement broadly, but her model for BSS translates well into higher education contexts. To help students identify their BSS, school officials should use the types of character traits Heumann emphasizes in Part 2 as a base. Introducing students to this way of understanding disability identity could serve as a powerful tool for both increasing student activism and for reforming institutional practices and policies.

Outside of BSS, Heumann’s emphasis on multiple identities in Parts 2 and 3 also offers useful insights for college practitioners. Recent work notes that, “knowing the relationship between meaning-making capacity and identity perceptions provides professionals who work with college students a deeper awareness of how students understand themselves” (Abes et al., 2007, p. 19). Heumann’s memoir offers first-person insight into how a disabled person makes meaning through her multiple identities. For example, when she writes that, “As a woman, I knew I walked a fine line between being seen as ‘strong’ and being seen as ‘unlikable’,” Heumann provides readers with a sense of how disability and gender influence the way she understands her positionality. Practitioners can use these meanings to better understand how disabled students construct their realities during college. Understanding these realities seems key for developing policies and practices that meet students’ most pressing needs.

Aside from considering disability’s intersection with other identities, Heumann notes that, “We also had to stay in touch with groups across disability” (p. 101). Heumann emphasizes the importance of uniting groups across specific disabilities to initiate collective action. She clearly recognizes that, “If we didn’t speak as one voice we’d never win” (p. 101). While Heumann’s message reaffirms the idea that all disabled people should be included, at times, her language privileges some disabilities’ claim to the disability identity over others. Heumann calls for organizations to look for diverse youth, “and not only the people with the mildest disabilities” (p. 197). The intent here is aimed toward fostering inclusion, but Heumann’s use of the phrase “mildest disabilities” suggests that some disabilities have less claim to the identity than others. To generate the most pressure on systems to change, language should be careful to avoid implying rank among disabilities.

Heumann offers readers a glimpse into what it can mean to live a disabled life in an ableist society. This book is well suited for nearly anyone in higher education who wants to understand some of the systematic barriers that disabled students face. Through that understanding, Heumann’s book offers the potential to inform policies and practices that are most relevant to student needs.

References


**About the Author**

Karly Ball received her B.A. in English Literature and Politics & International Affairs from Wake Forest University and her Master of Public Policy (M.P.P.) degree from the University of Virginia. She’s worked with postsecondary institutions, nonprofits, and patient advocacy groups as an assistant and independent consultant. She is currently pursuing a Ph.D. in Education and Inequality at the George Washington University. Her research interests include transition, disability identity, and policy. She can be reached by email at: kbball@gwu.edu.
JPED Author Guidelines

Purpose

The purpose of the Journal of Postsecondary Education and Disability (JPED) is to publish research and contemporary best practices related to college students with disabilities, college and university disability services offices, disability educators, and disability studies. Each article includes practical implications for disability services educators in colleges and universities. The JPED is peer-reviewed and uses a masked-in-both-directions review process. The sponsoring organization for the JPED is the Association on Higher Education and Disability (AHEAD, www.ahead.org), the primary source of disability-related expertise on accessibility, legislation, rights, and any other disability-related information as it pertains to higher education.

Manuscript Topics and Types

Published manuscripts will advance JPED’s purpose as detailed above (i.e., research, best practices, implications for disability services educators).

Research Articles

Manuscripts demonstrate scholarly excellence using one of the types of articles and papers as described in the Publication Manual of the American Psychological Association (7th edition, American Psychological Association [APA], 2020) sections 1.1-1.8 and 1.10.

Practice Briefs

Manuscripts describe innovative programs, services, or contemporary best practices that support college students with disabilities or disability services, and are organized using the following first-heading levels (APA 2.27):

- Summary of Relevant Literature: provide a succinct summary of the most relevant and contemporary literature that provides context for what is already known about the practice/program.
- Depiction of the Problem: provide a statement of the problem being addressed.
- Description of Practice: briefly describe the intended outcome for the innovative practice/program and how it has been implemented to date. Tables and figures may enhance specific details.
- Participant Demographics and/or Institutional Partners/Resources: provide a demographic description of participants and/or the offices/agencies that were collaborative partners (if relevant).
- Evaluation of Observed Outcomes: summarize formative and/or summative data used to evaluate the efficacy of your practice/program; support claims with evaluation data.
- Implications and Portability: discuss what has been learned and how this practice/program could be enhanced. Be honest about any challenges encountered. What could be done differently next time to achieve better outcomes? Provide a clear description of how and why other disability service educators should consider adapting your practice/program.

Book Reviews

Prior to preparing a book review, contact the JPED’s Executive Editor (jped@ahead.org) to discuss the book you are considering reviewing. Book reviews provide:

- An overview of the book, identifying the book’s stated purpose, the author’s and his/her viewpoint, and a general summary of the content.
- An evaluation of the book’s content, elaborating on the author’s objectives and how well those objectives were achieved, the organization and presentation of the book, and the strengths and weaknesses of the book along with the criteria you used for making that assessment. Recommendations should specify to whom you would recommend the book, why, and how you would suggest the book be used, and address its potential contribution to the field.

Manuscript Preparation

All manuscripts must be prepared according to the standards of the APA publication manual (7th edition). Authors submitting manuscripts to the JPED will be well-served to thoroughly understand Section 12 of the APA manual where the publication process is described as preparing for publication, understanding the editorial publication process, manuscript preparation, copyright and permission guidelines, and during and after publication.

When submitting a manuscript to the JPED, follow these specific guidelines:

- Submit one complete Word document (.doc
or .docx) that contains all manuscript components (i.e., title page, abstract, body, references, tables/figures).

- Provide a separate cover letter (APA 12.11) asking that the manuscript be considered for publication and stating that it has not been published, or is not being reviewed for publication, elsewhere.

- Manuscripts should have one-inch margins in 12-point Times New Roman font. Double space the abstract, body, and references; single space the title page and tables/figures. The length (of all manuscript components) for:
  ○ Research articles is between 25-35 pages.
  ○ Practice briefs is a maximum of 16 pages.
  ○ Book reviews is 800-1,200 words.

- The title (APA 2.4) should not exceed 12 words.

- Place the abstract (maximum 250 words, APA 2.9) on page two (following the title page). Include three to five keywords (APA 2.10) below the abstract.

- Use APA Section 1, Scholarly Writing and Publishing Principles, related to types of articles and papers; ethical, legal, and professional standards in publishing; ensuring the accuracy of scientific findings; protecting the rights and welfare of research participants and subjects; and protecting intellectual property rights.

- Use APA Section 2, Paper Elements and Format, to align paper elements, format, and organization. Indent paragraphs (APA 2.24), and adhere to heading levels (APA 2.27) to organize the manuscript.

- Content and method are important. Use APA Section 3, Journal Article Reporting Standards, related to overview of reporting standards; common reporting standards across research designs; and reporting standards for quantitative, qualitative, and mixed methods research. Please refer to Madaus et al. (2020) for research guidelines for higher education and disability where instructions are provided for describing samples and study locations, and appropriately selecting and describing the methodologies employed.

- Writing is important, carefully clean the manuscript; it is not the editor’s role to clean your manuscript so that it can be reviewed. Use APA Section 4, Writing Style and Grammar, related to continuity and flow, conciseness and clarity, verbs, pronouns, and sentence construction. Use APA Section 6, Mechanics of Style, related to punctuation, spelling, capitalization, italics, abbreviations, numbers, statistical and mathematical copy, presentation of equations, and lists. Refer to APA 6.32-6.39 to properly report numbers expressed as numerals or in words.

- Use APA Section 5, Bias-Free Language and Guidelines, related to general guidelines for reducing bias, and reducing bias by topic. Authors should use APA 5.4 to make an informed decision related to person-first or identify-first language. The JPED prefers person-first language unless the author can make the case for a preference of identity-first language.

- Use APA Section 8, Works Credited in Text, related to general guidelines for citation, works requiring special approaches to citation, in-text citations, and paraphrases and quotations. All citations must be referenced, and all references must be cited; avoid undercitation and overcitation (APA 8.1). Double-space and block quotations of 40 words or more (APA 8.27).

- Use a reference list (APA 2.12) not a bibliography; it follows the manuscript. Follow APA examples in sections 9-11; carefully clean references. It is not the editor’s role to clean your references.

- Tables and/or figures, following references, are in black and white only, and must conform to APA standards in APA Section 7. Follow examples related to table lines. Align numbers in tables to the single digit or the decimal. If tables and/or figures are submitted in image format (JPEG, PDF, etc.), an editable format must also be submitted along with a text description of the information depicted in the table/figure. This will be provided as alternate format in the electronic version of the JPED, making tables/figures accessible for screen readers.

- Do not include footnotes, instead, incorporate footnote narratives into the manuscript.

- Because of the importance of articles including practical implications for disability services educators in colleges and universities, authors will be well-served to include in the discussion a multiple paragraph subsection where practical implications for disability services educators are discussed.

- Before submission, ensure that the manuscript is ready by using strategies, examples, and checklists provided by APA:
  ○ Sample papers (pages 50-67).
  ○ Strategies to improve your writing (APA 4.25-4.30).
  ○ Tables checklist (APA 7.20).
  ○ Figure checklist (APA 7.35).
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○ In-text citation styles (Table 8.1).
○ Examples of direct quotations in the text (Table 8.2).
○ Reference examples (section 10 and 11).
○ Manuscript preparation (APA 12.9-12.13).

Manuscript Submission

Before you decide to submit your manuscript, authors are encouraged to read past articles in the JPED (available at https://www.ahead.org/professional-resources/publications/jped) to better understand the types of submissions we print. A manuscript must be submitted electronically as an attachment via email to jped@ahead.org, and must include the following:

• Subject line: JPED manuscript submission.
• Include in the body of the email a statement that you are submitting a manuscript for consideration for the JPED. Include the title of the manuscript and the full contact information for the corresponding author (APA 2.7).
• Attach to the email your complete manuscript, prepared as directed above, and a cover letter as outlined above.
• You will receive an email reply from Richard Allegra (Managing Editor of JPED) to confirm receipt of your submission within seven business days.
• Manuscript submissions by AHEAD members are especially welcome.

Upon Acceptance for Publication

For manuscripts that are accepted for publication, Valerie Spears (JPED Editorial Assistant) will contact the corresponding author to request:

• A 40-50 word bibliographic description for each author, and a signed copyright transfer form (Valerie will send templates for both).
• The JPED reserves the right to edit all material for space and style. Authors will be notified of changes.

Special Issues

The JPED occasionally publishes special issues which feature a series of articles on a particular topic. The JPED welcomes ideas for special topic issues related to the field of postsecondary education and disability or disability studies. The issue can be formatted as a collection of articles related to a particular topic or as a central position paper followed by a series of commentaries (a modified point/counter point). Authors who wish to discuss a special issue should contact the JPED Executive Editor at jped@ahead.org.

The topic and proposed authors need to be described. If the issue has the potential to be valuable to the readership of the JPED, the Executive Editor may provide suggestions for modification to content or format. If an agreement can be reached, the Executive Editor will share an agreement form to be completed and returned by the Special Issue Editor. The Special Issue Editor will inform authors of due dates and coordinate all communications with the contributing authors. The Special Issue Editor and the Executive Editor will be responsible for final editing decisions about accepted manuscripts.

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Editorial and Review Teams

The editorial team is composed of Valerie Spears, Richard Allegra, Ezekiel Kimball, and Ryan Wells. The review boards are comprised of more than 70 international disability scholars and disability services educators on college students with disabilities, disability services, disability studies, and research methodologies.

Reference

Publication manual of the American Psychological Association (7th ed.). https://doi.org/10.1037/0000165-000