Postsecondary Students and Disability Stigma: Development of the Postsecondary Student Survey of Disability-Related Stigma (PSSDS)

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Abstract

Few instruments or studies have been designed to measure the degree of stigmatization experienced by college and University students with disabilities. Yet, many researchers acknowledge through qualitative studies and other forms of experiential data that postsecondary students with disabilities do in fact encounter significant stigma effects. This study focused on the development, testing, and preparation for wider use of a Likert-type survey to measure self-reported degrees of stigmatization in college students with self-disclosed disabilities. The development of the Postsecondary Student Survey of Disability-Related Stigma (PSSDS) is part of a growing post-ADA effort to reduce stigma and make postsecondary education more accessible for students with disabilities.

Few issues in higher education have been more challenging and groundbreaking than the increasing application to and attendance of college by students with physical and psychological disabilities. Students with disabilities are attending two year and four year postsecondary institutions in record numbers. On the positive side, this is part of a larger trend in higher education that is moving in the direction of true universal access (Rose, Harbour, Johnson, Daley, & Abarbanell, 2006). However, as students with disabilities break through initial access barriers, they often discover that a complex layer of social barriers still remain beneath the surface, potentially interfering with their success. In simpler terms, it's not enough to simply get students with disabilities to college; it is tantamount to address the problems they face once they are actually there (Janiga & Costenbader, 2002; Trammell, 2005; Venezia, 2003).

Arguably, the most significant barrier to ongoing success and access for college students with disabilities remains a latent disability stigma. Stigma, for the purposes of this study, is defined as the social, academic, and psychological consequences of disclosing a disability, in this case formally to the disability support office. Students who self-disclose in order to receive accommodations for their disability place themselves at greater risk on a number of levels, possibly being subjected to: negative stereotypes associated with disability, inaccurate assessments of their ability to complete college level work, inappropriate judgments by peers, lack of accommodations outside of the classroom, or even increased likelihood of self-doubt and academic anxiety. Unfortunately, from a research standpoint the qualification and quantification of such stigma effects is notably difficult (Davis, 2006; Hartmann, 2003; Trammell, 2006; Wahl & NetLibrary Inc., 1999).

Coupled with the research challenges of studying perceived stigma is the difficulty of semantics. The labels used to define learning or learning-related disabilities—dyslexia, attention deficit disorder/attention deficit hyperactivity disorder (ADD/ADHD), bi-polar disorder—are modern inventions (though the disorders have been present for centuries) that result in inherently unstable identities (Davis, 2002). Young individuals with dyslexia, for example, have barely had to time to understand what dyslexia is, let alone what it means in a larger sense to be an individual with dyslexia. Few college disability support personnel would suggest that students with disabilities presently come to college equipped with a sophisticated disability identity, or have developed proficient adult skills in managing that identity (Perry & Franklin, 2006; Peters, 2006; Weyandt & DuPaul, 2006).

In the current postsecondary environment, more students with disabilities are attending college even as outdated and persistent barriers relating to disability stigma remain in place (Eudaly, 2002; Trammell, 2002a). The degree to which college students experience disability stigma firsthand has not been examined with the rigor that the demographic shifts might suggest would be helpful. Adequate attention has not been paid to disability (particularly in 18 to 22 year olds) as a stigmatizing identity in the postsecondary environment, especially in comparison to gender, race, and cultural studies. Disability in the postsecondary environment has essentially been neglected (Davis, 2002). This is in contrast to the P-12 research conducted over the last 30 years or more in the public schools relating to disability, which has resulted in a highly evolved etiology of special education and normalization (Bakker & Bosman, 2003; S. Field, Sarver, & Shaw, 2003; Wong & Donahue, 2002).

College students are rightly expected to be more independent and adept at self-monitoring than younger students. Assuming that they are equipped to handle complex social exchanges involving disability is at best erroneous and at worst discriminatory. Dating back to sociologist Erving Goffman's research on stigma in the 1960s, there is now a growing trail of evidence that suggests that disability becomes more difficult, rather than less difficult, to process as adults. Children at least have the small advantage of naivety; adults, on the other hand, generally have a better grasp of the group norms and rules, and are therefore more sensitive to their violation. College students, as adults, are quite vulnerable to real and/or perceived stigmatization when those violations occur (Canu & Carlson, 2004; Crocker & Quinn, 2000; Goffman, 1963; Levin & Laar, 2006; Olney, Brockelman, Kennedy, & Newsome, 2004; Price, Gerber, Mulligan, & Williams, 2005).

The degree of stigmatization, and the aspects of the college experience it most likely impacts, is suggested but far from quantified by past research. There is evidence, for example, that college students with disabilities may be hesitant to disclose to the college or University that they have a disability, in part because of the anticipated negative consequences of that action; that college students with disabilities may worry that accommodations will give them an unfair advantage, or that it will appear to others that they are not competitive; and on the positive side, studies suggest that students with disabilities have a genuine motivation to become more independent as learners after high school, and see the college transition experience as an opportunity to create a new, more autonomous, student identity (Janiga & Costenbader, 2002; Olney & Brockelman, 2005; Price et al., 2005; Trammell, 2000, 2003b; Trammell & Hathaway, 2007).

These anxieties can be compounded by a lingering notion that students with disabilities are not retained and do not graduate at the same rates as their peers without disabilities, in spite of the fact that some studies suggest otherwise (Belch, 2004; Getzel, 2008; Gilbert, 1996; Sydow & Sandel, 1996; Vincent, 1983; Wessel, Jones, Markle, & Westfall, 2009). Lack of disability accommodation is not tracked with the same rigor and consistency as more traditional variables for retention, such as socio-economic status, or established measures of student engagement. Few instruments exist to measure quality of college experience as it relates to disability. This is compounded by research deficits in the areas of postsecondary disability stigma, postsecondary disability and academic achievement, and community attitudes about disabilities at colleges and universities (Belch, 2004; Getzel, 2008; Reaser, Prevatt, Petschre, & Proctor, 2007; Seven Parent Populations, 2006; Trammell, 2003b; Wessel et al., 2009).

Taking into account all of these trends and situations, a timely argument can be made that the research community needs better ways to quantify postsecondary disability stigma. To put the matter in Foucauldian terms, power relationships between subjects and oppressors cannot be exposed until there is an open acknowledgement or recognition that oppression is actually occurring. The Postsecondary Student Survey of Disability-Related Stigma (PSSDS) was born of the quest to carefully measure and expose disability stigma that postsecondary students experience (Campbell, 2005; Gregory & Satterfield, 2002; Tremain, 2005).

Method

To measure a potentially nebulous social phenomenon such as disability stigma that is based in large part on the perceptions of various individuals, survey methodology offers attractive strengths and benefits (Deming, 2006; Dillman, 2000; Fowler, 2002). Most importantly, it gives the researcher an opportunity to focus on specific aspects of the disability experience that are most relevant or that emerge as impactful. Postsecondary student stigma is most readily measured in the areas traditionally associated with college success: academic achievement, social growth, and the development of a positive and independent adult identity (Skinner, 2004).

The PSSDS began qualitatively with exploratory student interviews and preliminary literature searches. Interviews with central Virginia college students who self-disclosed to disability support offices confirmed that many students with disabilities transitioned to college with anxiety about the negative stigma effects that could often be traced to earlier school episodes (Trammell, 2002b). Such episodes were typically related to the dangers of being labeled, being singled out, or being treated unfairly (Trammell, 2002b; Venezia, 2003; Zuker, 1997).

In the P-12 literature, studies across various age groups consistently indicated that disability stigma affected students with disabilities. In the early grades, for example, students began to treat classmates with labels differently (Bakker & Bosman, 2003). By high school, the social consequences of integration were still profound (Betancourt-Smith, 1994). An evolving outline of a larger problem began to emerge, a problem that would not theoretically disappear in college, only to reappear again in the work place or home later in adult life (Olney et al., 2004).

The literature, taken together, suggested an underlying factor impacting academic achievement (Trammell, 2006). Many studies for various types of disabilities mention an impact on grades. A recent study for ADHD confirmed a negative grade effect in a sample of college students (Frazier, Youngstrom, Glutting, & Watkins, 2007). Studies have indicated that accommodations don’t always result in higher grades for students with learning and learning-related disabilities (Trammell, 2003a, 2003b). Studies have also reported results suggesting that attitudes and other non-academic variables such as disability stigmatization were closely related to levels of academic success (Duranczyk, Goff, & Optiz, 2006). In summary, students with disabilities generally struggle more academically than their peers without disabilities.

A final complication resulted from the fact that many studies (including this one) relied on data generated from students who self-disclosed, and since many students with disabilities chose never to disclose, measurement error was inevitable and presented problems for generalization (Price et al., 2005). In other words, there was a high likelihood that the population of students who chose not to disclose was significantly different in some attitudes or habits from those who did disclose. Nonetheless, the evidence already cited also suggested that academic achievement and disability label and stigmatization were likely to correlate to a measurable extent even within the limitations of sampling students who disclose. In this study, as well as in many other sociological or psychological studies, being labeled was treated as synonymous with having the disability for purposes of analysis (Frank, 2004; Warshaw, 2006).

After organizing, coding, and analyzing the preliminary interviews and assimilating the stigma literature, a series of scaled questions was generated. The scale was modeled on Likert-type scales developed in the 1960s and 1970s mainly designed to measure race-related stigmatization during the Civil Rights Movement and several modern measures relating to HIV stigma, since no appropriate disability scale was available, (Berger, Ferrans, & Lashley, 2001; Utsey & Ponterotto, 1996). Referring back to the research methodology on race-related stigma, and employing current survey research methods, the collection of potential items was consolidated into approximately two dozen questions, each of which related to at least one of the major threads connected to learning-related disability stigma and college success, identified as: degree of academic success, quality of peer relationships, measurable sense of self and identity, and global awareness and/or concern about accommodations and disability-related issues (See Appendix).

Prior to formal administration, the survey was pilot tested with volunteer students with self-disclosed disabilities at various central Virginia postsecondary institutions. The results of the small pilot led to several questions being re-worded and other small editorial changes that made the questionnaire more accessible and understandable. The pilot results encouraged further development and use of the instrument which led to the formal study (Trammell, 2006).

Participants

The subjects in the formal study were college and University students with self-disclosed disabilities at three central Virginia postsecondary institutions: a major research University; an urban community college; and a small, private liberal arts college. The populations all had slight female majorities, were fairly evenly divided by year in school, and were pooled from the universe of up to several hundred students in any given semester utilizing the disability support services (DSS) offices. Various types of physical and psychological disabilities were represented, with the majority at each school being comprised of classic learning disabilities (dyslexia, etc.) and psychological disabilities (ADD/ADHD, etc.).

The intent was to capture as many students at each school as possible in a given semester, netting a sample of at least one hundred or more students overall. This would allow for adequate confirmatory factorial analysis, and also provide comparative demographic data between schools to increase generalizability (A. Field, 2005; Hughes, 2005).

All subjects participated voluntarily, with each student utilizing DSS services during the semester being offered an opportunity to complete the survey. Less than a dozen students declined to participate at each school when offered a chance to participate. Students were offered a pen or a pencil with an academic web site on it as a small incentive. Most students indicated a high degree of willingness to cooperate, especially since the directions explained that the ultimate use of the survey data would be to reduce campus disability stigma.

Results

One-hundred and twenty-one students completed the instrument, with roughly equivalent groups at each school (See Table 1). A one-way analysis of variance found no significant differences between the combined students in major demographic factors including gender ($f = .018$, $p > .05$).

Factor analysis (maximum likelihood) was calculated on variables thought to comprise specific areas or types of stigma that had been identified in previous research (the four areas already mentioned). An earlier exploratory factor analysis of the limited pilot data suggested seven variables present in the survey, four of which appeared to be very solid constructs. After final data collection, confirmatory factor analysis solidified the status of four important factors (See Table 2).

Using the estimated weights from the confirmatory factor analysis, the four variables established were matched with degree of perceived academic success (AS), quality of peer relationships (PR), measurable sense of self and identity (SS), and global awareness and/or concern about accommodations and disability-related issues (GA). These areas were developed in conjunction with a comprehensive literature review (Berube, 2005; Trammell, 2006).

The mean scores (See Table 3) provide some evidence that the students in the target sample were most stigmatized by worry about their standing with peers. They revealed themselves as least concerned or aware of global issues relating to disability and stigma in the larger cultural picture. The total scores indicated a diverse collection of stigma experiences, suggesting that the instrument allows for adequate sensitivity to differing experiences.

The overall Cronbach Alpha for the scale was .803, which by most research standards constitutes an acceptable degree of reliability (Field, 2005). In addition, an average deviation of 1.44 per item suggested that students did find appropriate sensitivity in the scale, since the range of possible responses was restricted to values of 0 through 4.

Table 1

PSSDS Demographic Statistics (N = 121)

School	Subjects (*n*)	Male/Female	Visible/Invisible
Large Urban University	36	38.9/61.1%	8.3/91.7%
Suburban Community College	46	45.7/54.3%	N/A*
Small Private College	39	43.6/56.4%	N/A*
TOTAL	*N* = 121	43.0/57.0%	N/A*

*Data not reported to protect confidentiality

Table 2

PSSDS Aggregate Factor Analysis (N = 121) using Maximum Likelihood Extraction and Direct Oblimin Rotation, with Seven Factors.[a]

Item #	1	2	3	4	5	6	7
Q17	[.968]						
Q12	.740			**.364**			
Q16	**.690**		.368	.318	-.323		
Q8	**.563**		.321				
Q2		**.915**				.346	
Q7		**.654**			.319	.379	
Q21		**.419**				.317	
Q18			**.759**				
Q13			**.586**				
Q11	.310		**.557**			.444	
Q20				**.575**			
Q15				**.557**			.353
Q14	.452	.431		**.507**			
Q9					[-.603]		
Q6	**.500**		.418		-.545		
Q22							
Q4		.354				**.801**	
Q5		.366				**.692**	
Q10		.363				**.634**	
Q19	.453					**.496**	
Q3		**.364**	.317			.493	
Q1						**.409**	

Q24							[.634]
Q23							[.610]

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[a] Items in the pilot subscales appear in bold. Items that fell out of their original pilot subscale are bracketed.

Table 3

PSSDS Mean Scores by Factor (N = 121)

Area	Mean Score	Sum Range
Academic Success (AS)	1.623	0 - 15
Peer Relationships (PR)	1.873	0 - 13
Sense of Self and Identity (SS)	1.495	0 - 14
Global Awareness (GA)	1.282	0 - 26
TOTAL STIGMA SCORE	39.338	10 - 65

Discussion

Including the pilot administrations, the PSSDS resulted in over 200 students from a variety of institutions completing and sometimes critiquing the instrument. The result was palpable evidence that disability stigma does impact students within the sample populations. Considering the institutional diversity and sample size of the formal study, there is credible evidence for expanding on this work and solidifying a construct that can better identity, explain, and help dismantle disability stigma at the postsecondary level.

The scores for each item on the scale were added, with some items reverse coded when necessary, so that a total range of scores between 0 and 96 was possible. Higher scores indicated that the respondent perceived greater disability stigmatization. Individual scores for the four sub scales were similarly added which cumulatively matched the total score for each subject.

Reliability of scores was increased through the mixed methods process of interviews, pilot administration and ongoing revisions of the instrument, and persistent attention to the literature on survey design (Lepkowski, Couper, Mathiowetz, Tourangeau, & Raghunathan, 2006; Litwin, 2003; Vogt, 2007). The questions, especially in the early phases of development, were challenged repeatedly for meaning and clarity.

Validity of scores was determined both by additional statistical analyses and traditional survey methods. In addition to reliability coefficients, the deviations provided evidence of validity for the purpose of establishing sufficient variability. A survey such as the PSSDS should be sensitive enough to capture real differences in respondents, but unified enough to identify patterns and latent variables. The social validity was largely established through the interaction with subjects in the interview and pilot phases.

The survey was designed from the outset to develop factors already present in the research, and in the anecdotal experiences of disability services coordinators. The object was to confirm those factors, and also to suggest simply that stigma is significant to the degree that colleges and universities, and specifically the DSS offices, should be targeting resources and programming specifically to reduce disability-related stigma. Accommodations will likely be more effective in a climate where disability is less stigmatized.

The use of the PSSDS has continued since the initial development of the survey, and is currently being used in conjunction with the Freshman Mental Health Project (FMHP) at a small private liberal arts college. There are plans to use it at other universities, possibly making the instrument available online through an organization such as the Association for Higher Education and Disability (AHEAD), so that DSS offices might make wider use of such an instrument.

On one level, the PSSDS only demonstrates what many disability activists and scholars might have already taken for granted. College and University students with self-disclosed disabilities do experience measurable degrees of disability stigma. However, in a day and age where resources are tied to accountability, and accountability to evidence, there is an extreme paucity of instruments like the PSSDS that specifically target students with disabilities, and other marginalized populations. The PSSDS may suggest the enormity of what remains to be done.

An evolution in the study of disability stigma might allow further questions to be asked, such as: What is the relationship between stigma effects and age? How can disability climate on campus be quantified and measured? How do different types of disabilities create different types of stigmas? How closely related to race and gender stigma is disability stigma (and are they additive)?

The hope and intention of research like the PSSDS is that others will follow and confirm, elaborate, and always advocate. Survey instruments also have the happy benefit of providing concrete evidence of effects that have perhaps always been suspected, but not so easily proven. With more proof in hand, there will be firmer grounds for securing resources and addressing needs of postsecondary students with disabilities that are not currently being met.

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Appendix

Postsecondary Student Survey of Disability-Related Stigma

Dear Student: Thank you for volunteering to fill out the following survey. When circling your responses, keep in mind your opinions and feelings as a student with a disability. On this survey, disability refers to disabilities of all types, visible or invisible. Please circle the appropriate response to the right of each statement and respond to every statement. Do not write your name anywhere; your choice to participate is voluntary, and your responses will ALWAYS remain anonymous. The scale runs from never to all the time. Keep the pencil!

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1. I think about my disability	never	occasionally	regularly	frequently	all the time
2. Students with disabilities don't receive as many opportunities as those without disabilities	never	occasionally	regularly	frequently	all the time
3. Teachers view me as having a shortcoming	never	occasionally	regularly	frequently	all the time
4. My friends think I'm different because of my disability	never	occasionally	regularly	frequently	all the time
5. People with disabilities are treated differently	never	occasionally	regularly	frequently	all the time
6. I think of myself as smart	never	occasionally	regularly	frequently	all the time
7. Students with disabilities are discriminated against	never	occasionally	regularly	frequently	all the time
8. Teachers view me positively	never	occasionally	regularly	frequently	all the time
9. I get along well with others	never	occasionally	regularly	frequently	all the time
10. Society stereotypes people with disabilities	never	occasionally	regularly	frequently	all the time
11. I feel frustrated about school	never	occasionally	regularly	frequently	all the time
12. Students with disabilities are successful	never	occasionally	regularly	frequently	all the time
13. I do poorly on tests in part due to my disability	never	occasionally	regularly	frequently	all the time
14. Other students are understanding about disabilities	never	occasionally	regularly	frequently	all the time

Please turn over and continue on the other side…

15. I get support from other students with disabilities	never	occasionally	regularly	frequently	all the time
16. I feel good about myself	never	occasionally	regularly	frequently	all the time
17. Students with disabilities are successful in the workplace	never	occasionally	regularly	frequently	all the time

18. My grades are lower than expected	never	occasionally	regularly	frequently	all the time
19. My disability causes strains to relationships	never	occasionally	regularly	frequently	all the time
20. I support other students with disabilities	never	occasionally	regularly	frequently	all the time
21. I feel that I am treated fairly on campus	never	occasionally	regularly	frequently	all the time
22. Students with disabilities need more support services and accommodations	never	occasionally	regularly	frequently	all the time
23. I ask for accommodations	never	occasionally	regularly	frequently	all the time
24. I talk to others about my disability	never	occasionally	regularly	frequently	all the time
25. Gender	Male	Female			
26. Age	20 or under	Over 20			
27. Disability	Invisible	Visible			

Thank you for completing this survey! Please return in the postpaid envelope provided, or leave with the survey administrator.