Supporting Students with Disabilities in Higher Education in the USA:  
30 Years of Advocacy

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Abstract

Over the past half century higher education in the United States has faced legislation which has challenged campuses to develop and implement policies and practices that effectively promote the access, retention, and graduation of students with disabilities. Students with disabilities, whose equal access to higher education has been mandated for the past 25 years by Federal legislation, notably the transition language in the Individuals with Disabilities Education Act (IDEA), Section 504 of the Rehabilitation Act and the Americans with Disabilities Act, have made a significant presence on postsecondary campuses. One unintended consequence of this legislation appears to be that institutions may be content with only meeting the letter of the law by providing accommodations and supports for equal access to the physical plant and to academic instruction, while neglecting other spheres of need. However, leading theories of persistence in higher education highlight both academic integration and social integration, as reflected in having a sense of “belonging” on campus, as key factors for student success. Emerging trends suggest that the next phase of progress for students with disabilities in higher education will be establishing and implementing shared norms about what it takes to make a campus barrier-free and welcoming – a place where disability is not seen as a marker of membership in a “special” group virtually nobody wants to be a part of but is, rather, accepted and appreciated as an element in a valued range of diversity.
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As important as Section 504 and the ADA have been, and as important as it is for people with disabilities to have access to legal remedies to overcome discrimination, compliance with the law is not enough. It is merely the starting point...universities and postsecondary institutions must move ‘beyond compliance’ and adopt new philosophies and approaches regarding students with disabilities (Taylor, 2003).

The Civil Rights movement that emerged in the United States in the 1960s focused on ending discrimination against Blacks, but it also inspired action by numerous other marginalized groups, including people with disabilities (Fleischer & Zames, 2001). People with disabilities were, however, different from other groups fighting for their rights because they also comprise a marginalized minority within those groups – a status that has been described as a “double or triple whammy” by making them liable to discrimination on at least two counts (Hollins, Downer, Farquarson, Oyepeju, & Kopper, 2002).

Education was a major battle arena as members and advocates of marginalized groups came together to demand equal access and treatment in the public school system and higher education. People with disabilities arguably faced the highest barriers of all since they were liable to be excluded from even attending school and many institutions of higher education (IHEs) routinely rejected applicants because they had disabilities (Paul, 2000). Significant victories came in the 1970s with passage by the U.S. Congress of what is now known as the Individuals with Disabilities Education Act (IDEA, 2004), which assures a “free appropriate public education” for children with disabilities ages three through 21, as well as Section 504 of the Rehabilitation Act of 1973 (Section 504, 1973), which prohibits discrimination against people with disabilities by educational institutions, including IHEs, receiving federal funding.

The Americans with Disabilities Act of 1990 (ADA, 1990) expanded this requirement to institutions not receiving federal funding. Later reauthorizations of the IDEA came to define special education’s ultimate purpose as the preparation of children with disabilities for adulthood, particularly with respect to “further education, employment, and independent living.” The IDEA supports this purpose by requiring that transition-to-adulthood services be provided to students in special education based on individualized transition plans developed by age 16 at the latest. Special educators and many parents commonly encourage students to aim for further education in the form of postsecondary learning, and research indicates this is listed as a goal in over 80% of transition plans of students with disabilities (Newman et al., 2011).

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The combination of special education and transition-to-adulthood services required by the IDEA and the nondiscrimination mandates of Section 504 and the ADA have been credited with increases in the rates of enrollment in higher education by people with disabilities (Wolanin & Steele, 2004). Disability in higher education may be examined from the perspective of (a) differences among students with disabilities (SWDs) or (b) disability as a component of diversity. With regard to the former, there is tremendous diversity among SWDs as to their kinds of disabilities, each of which tends to be associated with different sets of challenges. It is common to
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distinguish between disabilities that are (a) obvious or visible and therefore most likely to come to mind for members of the public in response to the term “disabilities” (e.g., conditions requiring wheelchair use, blindness) and (b) those that are hidden or invisible (e.g., learning disabilities, attention disorders). Fewer than 10% of SWDs have obvious disabilities, while the great majority has hidden disabilities (Newman, et al., 2011).

The predominance of hidden disabilities is significant when considering the provision of services, supports or accommodations for students with disability in higher education. One reason is that students with hidden disabilities are not visible on campus in the same way as students of color or wheelchair users might be seen, which is likely to leave the mistaken impression that disabilities are rare among students at an IHE. Another reason is that students with hidden disabilities are quite likely to want to keep them hidden due to the associated stigma, and therefore do not self-disclose to peers who might provide social supports, or on surveys used to estimate SWD numbers, or to obtain classroom accommodations and other supports to which they might be entitled under the ADA (Litner, Mann-Feder, & Guerard, 2005).

With regard to disability as a component of diversity in higher education, numerous diverse subpopulations have been identified and studied. To gain a view of the range of subpopulations and the attention given to them, numerous sources indicate SWDs have substantially lower retention rates than their peers without disabilities (Belch, 2005; Newman et al., 2011). SWDs are more than twice as likely to attend two-year than four-year postsecondary institutions (Newman et al., 2011) requiring such institutions to provide extensive student services often with a commitment to the development of the “whole person” (Braxton, 2009). Often students with disabilities are not a high priority for receiving support in accessing higher education. Another indication of the anomalous position of SWDs among diverse subpopulations is that they are often not included in the diversity initiatives provided by many IHEs to foster greater understanding of and connections between diverse student subpopulations (Higbee, Siaka, & Bruch, 2007).

Issues with a “Rights-based’ Approach to Students with Disability

Despite the passage of laws such as the Individuals with Disabilities Education Act (IDEA), the Rehabilitation Act, and the Americans with Disabilities Act (ADA) the post-school outcomes of employment and independent living continue to be dismal for individuals with disabilities in the United States. Little attention has been paid to the types of support provision legislated to be provided to individuals with disabilities and how such supports may be impacting the success of these individuals in different environments. There is evidence that since such modes of assistance are legislated, they are often applied differently in secondary school and in postsecondary school which negatively affects an individual’s successful transition. For example, at the secondary school level, where the Individuals with Disabilities Education Act (IDEA) mandate provision of assistance to youth with disabilities, assistance is geared around “services.” At the postsecondary level, where the Rehabilitation Act and the Americans with Disabilities Act (ADA) are the primary mandates, individuals with disabilities receive “accommodations” and “supports.” During secondary school years, educators are responsible for identifying and assessing students with disabilities, and with developing an Individual
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Education Program (IEP) that outlines each student’s assistance needs. Because of the prescriptive nature of the IDEA, there is a tendency for secondary schools to place students with disabilities in special classrooms for all or part of their curricula, deemed a “direct service”. At the postsecondary level, students are no longer covered under IDEA and must identify themselves as having a disability and must provide the school with documentation to prove their disability status. Postsecondary schools will tend to provide students with “accommodations” based on their type of disability (i.e., learning disability, visual impairment, etc.), and based upon a minimalist interpretation of the concept of “reasonableness.” There is a tendency at this level to provide assistance based on minimal access requirements to minimize cost.

Given the prescriptive legislative requirements of IDEA, assistance at the secondary school level is organized very differently than at postsecondary levels. Youth with disabilities often leave high school without the self-determination and advocacy skills necessary for them to describe their disability support needs as required in postsecondary education. The level and types of support offered decreases significantly as youth transition out of high-school, often leaving them without the assistance to which they have often grown accustomed. Because of the focus on meeting legal mandates rather than addressing broad student needs or long term goals, assistance provision in each environment are often short-sighted. The long-term goals of the individual with a disability are often disregarded in favor of “quick fixes” or compliance considerations.

The IDEA which contains definitions for IEP requirements, free appropriate public education, and various types of services (transitional, supplementary, etc.) is more prescriptive than definitions of assistance in the ADA. The IDEA focuses on “services” and “related services” for children with disabilities and “supports” for families, teachers and staff. The term “services” is used to cover anything that helps students with disabilities benefit from their special education, enables them to participate in general education, enables them to attain general education standards, or prepares them for transition out of secondary education. What and how services are offered is determined by the students’ IEP. IEP meetings consist of parents, teachers, agency representatives, service providers and the student, where appropriate. Each IEP is specific to individual needs and goals. The word “appropriate” is used by the IDEA often, and could be very subjective. Other important terms in the IDEA are “Least Restrictive Environment (LRE)” and “Free Appropriate Public Education (FAPE).” It should be noted that though these concepts may be intended to direct youth out of special classrooms wherever possible, youth with disabilities still tend to be directed into direct services that are provided in special classrooms.

Section 504 of the Rehabilitation Act was the primary legislation protecting access for individuals with disabilities in postsecondary education before the Americans with Disabilities Act. In general, section 504 prohibits any program receiving Federal support from discriminating against individuals on the basis of their disability. It applies to public entities or entities receiving Federal funds (as opposed to the ADA, which extends protection to the private sector). The responsibility of meeting the mandates of section 504 is the responsibility of the program. It is up
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to individuals with disabilities or the Federal government to press charges. The definition of “support” is much more varied in this Act, is used in terms like “support services,” “support staff,” “natural supports,” and “supported employment.” The distinction between “services” and “support” is ambiguous, since “support” is not limited to finances and can be direct to individuals with disabilities as well as indirect. In this Act, the term “support” may be a general term for any kind of assistance. The term “accommodations” does not appear frequently in the Rehabilitation Act, and not at all in section 504. However, “reasonable accommodations” is used in Federal regulations for employment based on section 504 in a manner consistent with its use in the ADA (45CFR Subtitle A § 84.12). At the age of 16, vocational rehabilitation services are available to eligible adults with disabilities, but are aimed at supporting preparation for employment rather than postsecondary education. Federal regulations for section 504 for postsecondary education and employment more closely resemble the ADA. Postsecondary institutions are required to make academic adjustments and provide auxiliary aids such as readers and accessible housing. The main premise of this subpart (45CFR Subtitle A, Part 84, Subpart E) is focused on nondiscrimination in the normal operations of postsecondary institutions such as admissions and financial aid. Under the Rehabilitation Act individuals with disabilities are responsible for identifying themselves, undergoing assessment and seeking out assistance, public institutions bear the cost of assistance provision, and focus is primarily on services and supports related to nondiscrimination.

The Americans with Disabilities Act (ADA), a civil rights act, applies broadly across environments. It covers both the public and private sectors, and it is often applied in conjunction with other laws. As with section 504 of the Rehabilitation Act, the ADA is much more open to interpretation than the IDEA. Under this Act, it is the responsibility of the individual to self-identify and provide documentation of disability. In high school, under the IDEA, the needs of individuals with disabilities are assessed and a plan is designed for them. However, after secondary school, once an individual identifies his or her disability, the kind of assistance an organization provides is determined by what is “reasonable” and would not impose “undue hardship” on the organization. The term “accommodation” emerges in the ADA, where it was rarely used in the IDEA or the Rehabilitation Act. In particular, “reasonable accommodation” is the defining point in terms of what institutions “have to” provide and what they “might” provide. Services for individuals with disabilities are required mostly in terms of “auxiliary services” (communication-related), which are defined much more narrowly than are services as defined by the IDEA. Another interesting usage of terminology in the ADA is “documented disability that significantly limits life activities.” This ambiguous phrase is another point of “have to” versus “might.” The courts are forced to interpret which activities are “life activities,” and how significantly they have to be “limited” in order to require an institution to provide accommodation.

Doing “What is Right” Beyond Compliance: Importance of a Sense of Belonging

The Disability Rights Movement was driven in large part by the resentment of people with disabilities in that they were viewed and treated as second-class citizens. Despite much progress in promoting the full inclusion of people with disabilities, SWDs who are given voice in interviews
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and focus groups still report, often with much emotion, that they face many barriers and often experience marginalization on campus (e.g., Denhart, 2008; Myers & Bastian, 2010; Najarian, 2008; Troiano, 2003). This is a matter of concern in view of the widespread understanding in higher education that students who feel accepted are more likely to persist and graduate than those who do not (e.g., Tinto & Pusser, 2006).

Research indicates that if new students do not start to feel like they “belong” within eight weeks of arriving on campus, they are at especially high risk for dropping out (Raley, 2007), while students who develop supportive networks tend to be more successful academically (Antonio, 2001; Thomas, 2000). It has been argued that having viable support networks may be particularly critical for SWDs in view of the greater challenges they are likely to face compared to their peers without disabilities (Mamiseishvili & Koch, 2010). SWDs, however, often experience stigmatization and social exclusion due to the negative attitudes of their peers and even faculty, or avoidance by others because of uncertainties about how to appropriately interact (Myers & Bastian, 2010; Nevill & White, 2011).

It is notable that a great deal of research and commentary has appeared in the higher education literature on how to make various underrepresented groups feel more welcomed and socially integrated on campus. In addition to the previously mentioned diversity initiatives, most large IHEs responded to racial anti-discrimination mandates by establishing or supporting centers or clubs for various racial/ethnic minority groups that serve as safe havens where students can support each other to better understand and negotiate the complex sociocultural and bureaucratic landscape of the IHE (Tinto & Pusser, 2006). However, SWDs may not find these centers or clubs welcoming, as negative and stigmatizing perceptions of disabilities are common in just about all racial/ethnic groups (McDonald, Keys, & Balcazar, 2007).

Faculty members have often been identified as a key target of efforts to make SWDs feel like they truly belong, as too many continue to appear to lack a good understanding of disability issues in the classroom (Getzel, 2008). Like many people in the wider society, faculty members may tend to doubt the claimed disability status of students with hidden disabilities and may not believe that classroom accommodations should be provided because they give them unfair advantages (Barnard, Stevens, Siwatu, & Lan, 2008). SWDs have often reported feeling such negative perceptions and, as a result, deciding not to seek accommodations that might prove important to their academic success (e.g., Litner et al., 2005).

Research on Social Integration Issues for Students with Disabilities

Given the social integration barriers often encountered by SWDs, one might expect policy makers and researchers to focus upon issues experienced by this subpopulation. However, it has been observed that there is surprisingly little attention or discussion of this topic (Belch, 2005; DaDeppo, 2009; Papasotiriou & Windle, 2012; Trammel, 2009). Rather, most attention is focused upon “technical” topics such as classroom accommodations, diagnostic assessments, and assistive technology access. “Technical” issues are viewed as extremely important for the academic integration of SWDs. It is understandable that attention would focus on how to reliably assess the unique needs of students in different disability categories and how to effectively respond to those
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needs, which typically involves medical, educational, or assistive technologies that can be applied at the individual level. Another factor, and perhaps a more significant one, is that disability rights or non-discrimination legislation may have had some unintended consequences by guiding attention to “equal access” as the predominant intended outcome (Taylor, 2003). IHEs typically responded to Section 504 and the ADA by establishing disability support services (DSS) offices responsible for ensuring that qualifying students gain legally mandated equal access (Madaus, 2000). “Equal access” has been primarily interpreted as referring to physical access to campus facilities (e.g., building entry ramps, accessible housing) and to accommodations and supports enabling participation in academic activities (e.g., note takers for students with hearing impairments). In contrast, equal access to the co-curricular domain (social, recreational, and other non-academic activities) has rarely been highlighted as a responsibility for DSS offices (Guzman, 2008; Loewen & Pollard, 2010). The essential need for supportive social relationships is not mentioned in either Section 504 or the ADA, and is apparently therefore seldom seen as a priority issue for DSS offices.

Envisioning a Future of Diversity and Disability in Higher Education

Described below are several emerging trends that hold promise for raising awareness of the total needs of SWD to be more socially and academically integrated on campuses. All of these trends point towards a possible future in which the campus climate is experienced by SWDs as welcoming and supportive so that all students feel like they truly belong.

Reorienting Disability Support Services towards the Social Model

Understandings of the causes of and appropriate responses to disabilities have commonly been classified as fitting either a medical or a social model. The medical model targets the individual for intervention, and potentially provides SWDs with essential supports for higher education success. Following a social model, disability is a social construction emerging from society’s environmental, economic, and cultural barriers to full social acceptance and inclusion (Fleischer & Zames, 2001). These models are not mutually exclusive but can complement each other. However, DSS offices, with some exceptions, have been critiqued as being guided almost exclusively by the medical model, which is congruent with the ADA’s orientation to ensuring equal access for individual SWDs but does not direct attention to important social issues of stigma and unwelcoming campus environments (Hadley, 2011). Wider adoption of the social model is expected to reorient DSS offices to expand beyond a narrow interpretation of equal access to also address campus-level social barriers and foster social inclusion (e.g., Gabel, 2010; Guzman & Balcazar, 2010; Strauss & Sales, 2010; Thornton & Down, 2010).

Enhancing Collaboration among Student Services

As advocated by Harbour and Madaus (2011), more collaboration among student services is needed to better address the physical and social barriers faced by SWDs. Currently various IHE offices and programs tend to be situated in what have been called bureaucratic “silos” with the DSS office typically considered to have primary or sole responsibility for supporting SWDs (e.g., Burnett & Segoria, 2009). The University of Connecticut provides a model for how the barriers inherent in silos can be broken down and commitment for supporting SWDs expanded (Korbel,
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Lucia, Wnzel, & Anderson, 2011). Key elements of the model include (a) having each DSS office staff member serve as a liaison to promote collaboration with specific departments across campus, and (b) conducting workshops on a range of disability-related topics for various student affairs units, which also serve as venues for developing collaborative partnerships. An example of the potential of cross-unit collaboration is provided by Wessel, Wentz, and Markle (2011), who described how at least five different offices at a university collaborated to organize a “power soccer” club so undergraduate power wheelchair users could participate in athletics, with those who were subsequently interviewed reporting enhanced friendships, greater self-confidence, and improved communication and interpersonal skills.

Including Disability in Diversity Initiatives

As noted earlier, many IHEs implement diversity initiatives, but these often fail to include disability. In line with the emerging idea that greater collaboration is needed across student services, DSS offices might work with those involved in diversity initiatives to strengthen or add a focus on disability (Higbee, Siaka & Bruch, 2007). This would provide an avenue for promoting social model language about disabilities moving away from the deficit orientation inherent in medical model descriptions of SWD. For example, Depoy and Gilson (2008) promote use of the terms typical and atypical to highlight the fact that human characteristics occur along a continuum and also to avoid the value judgments inherent in commonly used terms such as normal and abnormal, which imply a binary division rather than a continuum. In this vein, there has been increasing use of the term neurodiverse (as opposed to neurotypical) to describe people with disabilities such as autism, learning disabilities, attention disorders, or certain psychiatric disorders. Neurodiverse individuals may in fact have advantages in certain situations and occupations such as the attention to detail that many people with autism can bring to a task (Armstrong, 2010). Research also suggests that people with disabilities achieve more positive self-identities when they are able to “reframe” problematic personal characteristics as lying on a continuum of diversity rather than being outside the range of normalcy (Hahn & Belt, 2004; Olney & Kim, 2001). As use of neurodiverse and other non-stigmatizing terms becomes the standard, we can expect SWDs to gain enhanced feelings of belonging that in turn support the development of more positive self-identities and greater willingness to self-disclose in order to access services and supports promoting improved social and academic outcomes.

Extending Universal Design to the Co-curricular Domain

Ensuring equal access often involves use of universal design principles, which refers to the modification of environments and activities so they are accessible to everyone, no matter their functional limitations (Roberts, Park, Brown, & Cook, 2011). Universal design is best known with regard to physical access, while what is known as universal design for learning is increasingly being used to make educational materials and activities more accessible for students with a wide range of learning styles and physical and sensory abilities. Universal design for learning holds the promise of helping to “normalize” the higher education experience of SWDs by reducing the need for them to self-identify and followed detailed procedural steps necessary to obtain classroom accommodations. The universal design approach also has the potential to improve access to the
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cocurricular domain (e.g., large screen transcription of announcements and speeches at public events) (Belch, 2005; Johnson, 2000; Strange & Banning, 2001).

Promoting Change through Student Activism

The Disability Rights Movement has achieved many successes largely because people with disabilities have stood at the forefront and become visible as fellow human beings. The frontline advocacy of SWDs themselves may also be essential to successfully prompting IHEs to do what is needed to create campus environments that are truly welcoming for all. The Beyond Compliance Coordinating Committee at Syracuse University provides one model for student activism. According to the organization’s website (http://bcccsyracuse.wordpress.com/), it was founded in 2001 by a group of graduate SWDs with membership open to all students. The organization has held numerous awareness-raising events and worked with the university administration to change policies and practices. The committee has achieved national reach through publications and conference presentations and its model has been adopted at other IHEs. Another organization working to strengthen the collective voice of SWDs is the Youth Legacy Foundation. Its activities include a Higher Education Network (currently focused in Minnesota) designed to link student groups at different IHEs so they can share resources and expand their impact and reach (http://youthlegacyfoundation.org/?page_id=621).

Assessing Progress in Creating Welcoming Campus Climates

The various activities described above may be viewed as components of a broader initiative to transform what has been called the “campus climate” so it is experienced by SWDs as welcoming and fully accessible (Huger, 2011; Wilson, Getzel, & Brown, 2000). Over the years a number of instruments have been developed to assess how welcoming the climate is for diverse student subpopulations, including several specifically for students with disabilities. The College Students with Disabilities Campus Climate survey is comprised of 43 six-point Likert scale items (Lombardi, Gerdes, & Murray, 2011). The Assessment of Campus Climate to Enhance Student Success consists of several questionnaires that gather the perspectives of administrators and staff, faculty, and students (Vogel, Holt, Silgar, & Leake, 2008). AHEAD offers a service to administer these questionnaires online and produce summary reports (http://www.ahead.org/program_eval_tools). Stodden, Brown, and Roberts (2011) provided a brief climate assessment tool consisting of 10 “agree” or “disagree” items (derived from a set of larger instruments on attitudes to people with disabilities, programmatic supports, facilities access, and instructional access) along with a scoring guide. Such instruments can be used by faculty and administrators to evaluate and improve their programs to better serve SWDs, and by SWD groups to validate their advocacy efforts to promote change and track the extent to which change is happening over time.

Conclusion

The ultimate goal of the Disability Rights Movement has been to reach a point where everyone is viewed and treated as deserving of respect and full social acceptance. Higher education can play a leadership role in attaining this goal by creating inclusive and welcoming campus environments that serve as models for the wider society. Such environments are not legislated or
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legally required, as they would be based on changed attitudes and behaviors typically not possible to legislate. The development of welcoming attitudes and behaviors would instead seem to require continued advocacy by concerned individuals with and without disabilities who work to define and spread enhanced norms about what an IHE should be. Issues to consider include:

- Promote the benefits to higher education as a place of valuing and seeking out diverse ways of perceiving and thinking. This would require campuses to work toward a culture of exploration, acceptance and support for and by a diverse range of teachers and learners.
- Advocate making campuses barrier-free and welcoming, physically, programmatically, and attitudinally. While many people may support this statement, it is imperative that SWDs and other marginalized students take up the charge for higher education campuses to be truly welcoming and supportive for all students. This requires that training (self- and group-advocacy) and support be provided to SWDs to step into the lead.
- Increase the proportion of faculty and staff with disabilities and other diverse characteristics on campuses, to raise the visibility and status of such persons and provide SWDs with more potential role models, mentors, and advocates.
- Give more attention to social integration issues for SWDs within the context of diversity. It is important to seek out and involve social scientists and others in this effort – too many times only researchers and advocates in the disability field are involved, which amounts to “preaching to the choir.” Research is especially needed on SWDs who are liable to face discrimination on other counts, such as being of ethnic/racial minority heritage or having a non-normative sexual orientation.
- Raise awareness of these issues broadly by publishing research articles and advocacy pieces in academic journals and general audience publications outside disability fields.

As the social model of disability continues to impact upon how disability services, supports, and accommodations are provided in higher education, increased opportunities will become available to support SWDs within the broader context of supporting all students to successfully access, retain, and complete the program of study of their choice. Furthermore, as SWDs are supported to rethink about themselves and others on a continuum of diversity, it is expected that all learners will feel a sense of belonging and express their needs to be successful learners, free of the restrictions and stigma that come with labels. Once campuses have become places where all students are supported to learn, regardless of their diverse needs, then we can all begin to feel the shift from a “rights based approach” to a “what’s right” approach to supporting SWDs in higher education.
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