

Musings of Someone in the Disability Support Services Field for Almost 40 Years

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Abstract

As the title states, this article is a collection of musings with only modest attempts at establishing an order for them or connections between them. It is not quite “free association,” but it is close. This structure or perhaps lack of it reflects the variety of things we do in our work. Many of the things we do have little in common with each other than providing access. Topics discussed include working with Vocational Rehabilitation Agencies, parents of students with disabilities, and the Office for Civil Rights. Suggestions for professional training are offered. Support/service animals and technology are discussed as well.

Keywords: Disability, accommodations, Higher Education, Americans with Disabilities Act, Office of Civil Rights, ADA, OCR

As the title states, this article is a collection of musings with only modest attempts at establishing an order for them or connections between them. It is not quite “free association,” but it is close. The editors of this Special Edition of the *Journal on Postsecondary Education and Disability (JPED)* were gracious in inviting me to write an article discussing our field. In an aside, one editor also wrote, “We really hope you’ll feel free to take the gloves off and speak your mind!” Let me quote from the movie *The Big Chill* (Nasatir, 1983) and say, “Be careful what you want for you may surely get it.”

Our Work Works

Over the past thirty years, there have been many studies comparing employment rates for postsecondary alumni with disabilities to other people with disabilities. One of these was done at Ball State (Markle, 2007). We replicated the Ball State study at the University of Michigan in 2009, though our findings were not published. These studies found that unemployment and underemployment among people with disabilities were significantly reduced when the person

had a postsecondary degree. In 2012, the U.S. Senate Committee on Health, Education, Labor and Pensions used Bureau of Labor Statistics data to note:

Post-secondary education directly translates into higher pay and lower unemployment. According to the BLS, in 2011 the median weekly earnings for a person with a high school diploma were \$610 per week compared to \$1,016 for a person with a bachelor’s degree (p.19).

These studies and others supporting the success of Disability Support Services (DSS) programs make it very paradoxical that, when the Americans with Disabilities Act of 1990 (ADA) was passed, many Vocational Rehabilitation (VR) Agencies cited the ADA and determined that they were no longer obligated to provide services such as interpreters for their clients who were enrolled at colleges and universities. One by one, State VR agencies, over protests by the Association on Higher Education And Disability (AHEAD) and others, divested themselves of the responsibility to provide support services by pointing to an irrelevant piece of legislation and ignoring three court rulings

that found them to be the “first payer” when a student was also a client (*U.S. v. University of Alabama*, 1990; *Jones v. Illinois Dept. Rehabilitation Services*, 1982; *Schornstein v. N. J. Div. Voc. Rehab*, 1981). VR agencies may not be the partner we once had, but students with disabilities who go on to higher education are more likely to be employed nonetheless. Stated more succinctly, “Our work works.”

Suicide is Painless...It Brings on Many Changes (Mandel & Altman, 1970)

The Department of Justice’s (DOJ) elimination of “danger to self” as a reason for requiring that a student leave a university to get treatment has proven worrisome (Grasgreen, 2011). Students who are now “protected” from dismissal have gone on to kill themselves (Grasgreen, 2014). We need to remember that we still have the option to remove a student based on how their behavior affects other students. I speak as someone who, as an undergraduate personal care attendant, had to clean up after a student I was working with had slit his wrists. In retrospect, that was a student we probably should have withdrawn, as his next attempt was successful. As an Assistant Dean of Students for a couple of years, I had many occasions to observe the devastating impact of a suicide on roommates and classmates. Even suicidal ideation can ruin a semester for the students who hear about it. This kind of disruption is an excellent reason to remove a student while they seek help. The elimination of “danger to self” was a severely misguided change. Fortunately, we do still have ways we can address these concerns by using the disruptive impact the behavior has on others.

Black Hawk Parents

We all have stories about Black Hawk parents. It is a very rare occurrence relative to the number of highly supportive parents, but they are nonetheless a challenge for us. I have seen parents pretend to be their son or daughter and send email to me and faculty from the student’s account. I actually have proof of this, as one parent pretending to be her son mistakenly signed her own name. I have had a parent move into a student’s apartment in order to coordinate the student’s life for him. I have seen a couple of these students graduate, but I question their ability to function effectively and independently within a work environment. *The Chronicle of Higher Education* reported that some universities are creating offices to serve parents (Galsky & Shotick, 2012). Other than Parking Operations, I can’t imagine a worse place to work.

In a slightly related matter, in one instance the Department of Education’s Office of Civil Rights (OCR) told a school to put less responsibility on a student to arrange their own support services. OCR seemed to equate our practice of requiring student involvement in setting up their support services to making voter registration difficult for African Americans: a sort of discrimination through bureaucracy. In reality, we have a commitment to student development that they do not always share. I think this confusion is exacerbated by the fact that much of the communication between OCR and ourselves is site visits and letters of finding. Paul Grossman, former Chief Regional Attorney for the U.S. Department of Education/Office of Civil Rights and now member of the Board of AHEAD, is the most obvious and welcome exception. I know that AHEAD also has plans to broaden communication between OCR and our profession. We need to be doing similar things to increase our communication with VR officials and K-12 special education personnel. The “silos” in which all four of these groups operate do not serve students well.

Why Can’t We All Just Get Along?

Recent OCR rulings seem designed, in part, to designate DSS as having the definitive last say in accommodation decisions (“Settlement Agreement,” 2012). This support is appreciated, and I suspect OCR personnel know full well that many DSS staff do not get the support they need from within their institutions. However, it is an indisputable fact that, in the matter of accommodations decisions, faculty also have an important role. At Southern Illinois University, I cannot presume to know what is essential to the education in each of the institution’s hundreds of degree-granting programs and several thousand different classes. It would be a rare DSS professional indeed who could claim such knowledge of his/her university’s curricula. The secret to making the faculty-DSS partnership work might be for us to stay with what we know and faculty to stay with what they know. But this seems to be difficult for both parties. All of us have heard of cases like *Guckenberger v. Boston University* (1997) where the President, a humanities instructor, wanted to see documentation for students with learning disabilities and we reciprocate by telling them how to design their classes using Universal Design. We must all tread carefully and with respect when advising others as to how they should do their work.

Getting Horton to Hear Us Whos

(Seuss, 1954)

As I noted previously, the OCR seems to be trying to empower us. Many of us have just about everything working against us and we desperately need the support. Studies have shown that many DSS professionals are young and new to the profession (Kasnitz, 2013). By and large, we enter this field to “do good,” not to stare down architects unwilling to put a ramp on a historic building. Most of us have bachelors and master’s degrees, not the Ph.D.’s held by the faculty to whom we must propose accommodations. The degrees we have are in fields such as counseling and teaching, not law and business, and we are disproportionately female. Faculty, on the other hand—and this is especially true in the sciences—are disproportionately male (National Center for Education Statistics, 2013). In this, the twenty-first Century, a sex-based power differential is abhorrent but it is nonetheless a reality. None of these things are insurmountable, but they do make our work more challenging. What is the solution to this dilemma?

I think AHEAD and others must make a concerted effort to both develop our members’ abilities to get things done and be effective agents for change on campuses. I believe the primary responsibility for this matter falls to AHEAD, in part because there are almost no degree programs to teach people to do the work that we do. I know that efforts are underway to try and get a handle on what kinds of training our members might find useful in this regard.

Pay It Forward

On a regular basis, I see people who seem to have been randomly assigned to DSS work or, as a colleague put it, “selected from among onlookers at a recent parade!” Through no fault of their own, they are writing to the listservs and clawing for information to resolve issues ranging from the most basic to the highly complex. Good informational publications exist but fall short of providing information helpful in resolving the more nuanced issues of the field, which is most of it. My editor challenged me to find examples of this. It wasn’t hard. Below is an email from DSSHE-L@LISTSERV.BUFFALO.EDU:

I received documentation that included results from a NeuroTrax Computerized Cognitive testing. I’ve never heard of this testing instrument before and am unsure of its relevancy. I tried searching on the Internet for additional information about

said testing and only found information from the company that created it. Has anyone been provided with this kind of testing and did you accept it? (Jackie S., 2014)

While many of us were given these responsibilities as an afterthought, those of us who were lucky were mentored by someone in the field. I once went out to lunch with my mentor, Ron Blosser, who was a pioneer in the field and the person for whom AHEAD’s “Blosser Award” was named. Ron picked up the check. When I protested, he told me to buy a meal for one of my student workers someday. Several years later, I bought dinner for Emily Singer Lucio and gave her the same instructions. She told me that she not only took her staff member to lunch but also employs her as a baby sitter. Emily further stated that this person is now an applicant for her own professional position. “Pay it forward,” everyone.

Our Cynophobia (abnormal fear of dogs)

Since the passage of the ADA Amendments Act (ADAAA) in 2008, the listservs used by our profession have been inundated with questions about service and support animals. Because we tend to over-focus on this area, I would like to share a successful strategy for dealing with service/support animal issues.

The psychologists and doctors who write less than believable notes to us stating that Spot is needed for Suzie’s mental health are far less likely to continue this charade if they have to explain it to a medical colleague. When you receive the rare questionable documentation advocating for the presence of a mental health tarantula, require the student to sign a release permitting their physician to speak to a physician at your health center. Such a conversation often produces different results from what they scribble on prescription pads for our consumption.

Disabilities Must Manifest Themselves as Something Actual

My father is retired faculty, and many years ago we coauthored some articles for JPED that focused on our respective disciplines and the emerging number of students with learning disabilities (Goodin & Goodin, 1988). In one of these articles, he wrote, “...disabilities must manifest themselves as something actual” (p. 16). It seemed simplistic to me at the time, but I now believe that *Bartlett v. New York State Board of Law Examiners* (1997) would not have gone in our favor had the judge not asked her to read aloud in the courtroom.

Marilyn Bartlett's less than fluent reading demonstrated that her learning disability (LD) manifested itself as something actual. In writing this essay, I asked Marilyn if I remembered the events correctly (we are friends on Facebook). She wrote back:

I do believe that [Judge] Sotomayor took into consideration that horrible day when she asked me to oral read. That added to my explanation of how I discern the difference between "b," "d," "p," and "q" (Look at them, they are indeed all the same letter. It is a matter of the position of the "circle" and the "line!"), the answer dawned on her and it was clear: I was using my intellectual power to cognitively figure out the letters, then acquired encoding skills in order to string together sentences, but all without automaticity (the ability to see the same word the same way twice).

So, based upon the totality of the evidence, Sotomayor decided I was substantially limited in the major life activity of reading and working. The big thing is that Sotomayor realized that such a decision needed "clinical observation." It would be impossible, just talking to me, to figure out that my disability was orthographically as well as phonologically based.

Have I said too much? Or have I confirmed your father's thinking?? (M. Bartlett, personal communication, April 24, 2014)

She obviously confirmed my father's thinking.

It is understandable that documentation standards for diagnosing LD were rigid thirty plus years ago because LD was essentially new to our field and we needed specific guidelines to follow. As we learned more about it over the years, we relaxed our documentation requirements. For example, many of us had three-year age limits on documentation. Looking back, that was a waste of time and resources for many students whose disabilities essentially would not change over time. Removing the three-year rule was a huge step in the right direction, as there is no need to keep retesting for what is a static condition. This move towards a less rigid approach continued with the ADAAA recommending the use of self-report as a means of updating old documentation. AHEAD's documentation guidelines (2012) are very helpful in making the transition to less reliance on documentation, as well. However, I feel that self-report by students or observations by teachers in high school or grade school should not be enough to diagnose LD. Initially, a full battery of achievement and aptitude tests should be used to diagnose LD. This testing

gives us so much insight into students' abilities. I'm fine with using Individualized Education Plan (IEP) updates or summaries of performance (SOP) after that, but initial testing should be done to establish the disability in the first place.

We have to be wary of requiring too little or no testing for diagnosis or we can lose credibility with faculty. We fought hard to show that support services for students with disabilities are not an unfair advantage and, if we become too lenient, we weaken that argument. In short, a disability must manifest itself as something actual.

Disability as a Weapon and Faculty as the Enemy

It worries me greatly that faculty at institutions that widely open their doors in an effort to admit all types of students are more frequently subjected to abusive behavior by students with disabilities who are adept at manipulating faculty to obtain better evaluations than they deserve. A faculty member once used the term "disability as a weapon" when describing such a student to me. The student was academically marginal and was known to threaten lawsuits repeatedly unless he won arguments about grades. As an example, I would point to *McInerney v. Rensselaer Polytechnic Institute* (2013). The student in question was described as "confrontational, aggressive, demanding, inflexible, belligerent, manipulative, and irrational." He eventually brought nine complaints of disability discrimination to a court and all nine were dismissed.

I have been told of instances in which faculty did give undeserved grades to students to avoid the antagonism described above. One day, this is going to backfire on us badly. Students' civil rights may not be denied, but there will be other repercussions. Will my faculty in the School of Architecture be willing to spend countless hours outside of class to make their field accessible to a blind student if they feel abused? Will my faculty member in Mathematics, excellent with students who almost seem to have dyscalculia, continue to appreciate the challenge of teaching them if he is afraid of a lawsuit?

I fear that OCR is in position to see many instances of problematic faculty and could accept, to some extent, the "faculty as the enemy" mentality. It is unfortunate that they have never met the faculty in my School of Architecture or my instructor in Mathematics.

There are, of course, faculty who blatantly refuse to provide what is clearly a reasonable accommodation. However, the few times I have encountered a faculty member who was outrageous in how he was treating a student with a disability, upon further inspection it

quickly became obvious that he was outrageous in other ways. These are not easy situations to deal with, but I do have some suggestions. Very early in the discussion, before positions become entrenched, contact the department chair. They are often able to resolve such problems in quiet and non-ego-threatening ways. I would not use the law as my first way to convince the faculty to make the accommodation. I would, however, use the Wiley legal database of disability related OCR cases and court rulings to find similar cases and share them with the department chair. The Wiley database is open to members of AHEAD and available via AHEAD's website.

Robotic Exoskeletons and Other Technology

Some of the most important advances in technology have resulted from repurposed technology. As an undergraduate employee in a wheelchair repair shop, my colleagues and I noted the development of the lightweight wheelchairs predominantly being used by athletes at that time. After we managed to get ahold of one, we made a few modifications to the foot pedals and then had a student with spina bifida sit in it. With one push, she traveled the full length of a hundred foot hallway. As she breezed past me, she said, "This must be what walking feels like."

High-speed document scanners have been around forever. When DSS programs began scanning documents, most of us had flatbed scanners that scanned one page at a time. I went to an office supply store looking for a faster flatbed scanner and was amazed upon seeing my first high speed sheet fed Canon DR-9050C. I could not believe these things were not being used by any DSS programs that I knew of. Recent examples of useful innovations include the Livescribe pen and the Ginger Grammar and Spell Checker.

Technology designed exclusively for people with disabilities has not always been as successful as those described earlier. Kurzweil 3000 is expensive compared to products you can get at Best Buy, which do roughly the same thing. JAWS is also quite expensive relative to the Apple IOS, which is accessible out of the box. Come to think of it, I have not met any paraplegics walking around in NASA robotic exoskeletons either.

In Conclusion...Caroling

I got into DSS for two reasons. One was the notion that improving one's mind could overcome whatever obstacles a disability might impose. The other was a moment that had occurred as an undergraduate, when I was asked to drive a bunch of DSS folks to the airport after an early DSS conference. It was winter, and they sang carols the whole way there. I sat up front, thinking that these were the people I wanted to hang out with. Despite some of the issues described above, these two convictions continue to guide and energize my commitment to the DSS field. I'm sure there will be many more changes in the field over the next thirty years, but I hope that whatever those changes bring, there will still be moments when we gather to sing carols and that a passion for helping our students overcome obstacles will still guide us.

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About the Author

Sam Goodin received his B.S. degree in psychology from Southern Illinois University (SIU) and M.S. also from Southern Illinois University. Sam worked in Specialized Student Services at Southern Illinois University throughout his undergraduate and graduate work. He went from there to a counseling position at the University of North Dakota's Disability Support Services Office. He then directed disability support services programs at Indiana University, California State University Los Angeles and the University of Michigan. He worked as an Assistant Dean of Students at the University of Michigan until returning to SIU to direct the Office of Disability Support Services.

Sam has been very active in the Association on Higher Education and Disability (AHEAD). He has numerous publications and conference presentations and served as the President of AHEAD. In 2003 he was awarded AHEAD's Ron Blosser Dedicated Service Award. This award is named after the person Sam reported to throughout his graduate and undergraduate work at SIU. Sam can be reached by email at sgoodin@siu.edu

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