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# UNDERSTANDING AND SELF-ADVOCACY

## Students with Learning Disabilities, Unrecognized Talent

By Tabitha A. Mancini

F. Scott Fitzgerald<sup>1</sup>

Gavin Newsom – Former Mayor of San Francisco and current  
Lieutenant Governor of California<sup>2</sup>

Leonardo De Venice<sup>3</sup>

Magic Johnson<sup>4</sup>

Whoppi Goldberg<sup>5</sup>

Woodrow Wilson<sup>6</sup>

Paul Orfalea – Founder of Kinko's<sup>7</sup>

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1 Institute for Human Adjustment, University of Michigan. “Dyslexia Success Stories Dyslexia Help at the University of Michigan.” Dyslexia Help at the University of Michigan. <http://dyslexiahelp.umich.edu/success-stories/famous-authors-with-dyslexia> (accessed October 7, 2012)

2 Davids Landau, Meryl. “Colleges Step Up to Meet Dyslexia Challenge - US News and World Report.” US News & World Report News & Rankings Best Colleges, Best Hospitals, and more. <http://www.usnews.com/education/best-colleges/articles/2011/09/27/colleges-step-up-to-meet-dyslexia-challenge> (accessed October 7, 2012).

3 Institute for Human Adjustment, University of Michigan. “Dyslexia Success Stories Dyslexia Help at the University of Michigan.” Dyslexia Help at the University of Michigan. <http://dyslexiahelp.umich.edu/success-stories> (accessed October 7, 2012).

4 Institute for Human Adjustment, University of Michigan. “Dyslexia Success Stories Dyslexia Help at the University of Michigan.” Dyslexia Help at the University of Michigan. <http://dyslexiahelp.umich.edu/success-stories> (accessed October 7, 2012).

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6 Institute for Human Adjustment, University of Michigan. “Dyslexia Success Stories Dyslexia Help at the University of Michigan.” Dyslexia Help at the University of Michigan. <http://dyslexiahelp.umich.edu/success-stories> (accessed October 7, 2012).

7 Orfalea, Paul. *Copy This!* New York, NY: Workman Publishing Company, Inc., 2007.

Henry Ford<sup>8</sup>

Dale S. Brown – “Key player in the development of the Americans with Disabilities Act”<sup>9</sup>

Steve Jobs<sup>10</sup>

Jack Horner<sup>11</sup>

Charles Schwab<sup>12</sup>

Albert Einstein<sup>13</sup>

What would our daily lives be like without these people? My overall project looks at the relationship between diagnostic testing and self-advocacy for students with learning disabilities (LD), specifically within post-secondary education. The significance of this research is to make visible the attitudinal barriers within the bureaucratic process of higher education for a population that is extremely marginalized, resulting in devastating social consequences.

Today, I will explore attitudes grounded in conceptions of “economic value” that create institutional/bureaucratic barriers to the possibility of self-advocacy for these students.

Methodologically, I used in-depth semi-structured interviews. The first phase of the project was to interview professionals within the field of learning disabilities, i.e. staff members who work with

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8 Institute for Human Adjustment, University of Michigan. “Dyslexia Success Stories Dyslexia Help at the University of Michigan.” Dyslexia Help at the University of Michigan. <http://dyslexiahelp.umich.edu/success-stories> (accessed October 7, 2012).

9 Brown, Dale S.. “Learning Despite Learning Disabilities.” LD OnLine: The world’s leading website on learning disabilities and ADHD. [http://www.ldonline.org/firstperson/Learning\\_Despite\\_Learning\\_Disabilities](http://www.ldonline.org/firstperson/Learning_Despite_Learning_Disabilities) (accessed October 7, 2012).

10 Institute for Human Adjustment, University of Michigan. “Dyslexia Success Stories Dyslexia Help at the University of Michigan.” Dyslexia Help at the University of Michigan. <http://dyslexiahelp.umich.edu/success-stories> (accessed October 7, 2012).

11 West, Thomas G.. *In the mind’s eye: visual thinkers, gifted people with dyslexia and other learning difficulties, computer images, and the ironies of creativity*. Updated ed. Amherst, N.Y.: Prometheus Books, 1997.

12 Institute for Human Adjustment, University of Michigan. “Dyslexia Success Stories Dyslexia Help at the University of Michigan.” Dyslexia Help at the University of Michigan. <http://dyslexiahelp.umich.edu/success-stories> (accessed October 7, 2012).

13 Wolf, Maryanne. *Proust and the squid: the story and science of the reading brain*. New York, NY: HarperCollins, 2007.

these students and testing administrators who test and diagnose LDs (primarily psychologists). I then thematically coded the data. Over the 2012/2013 school year, I will begin the second phase of the project by interviewing students with learning disabilities to hear their “voices” and how they experience this issue. My data was and will continue to be gathered in Northern California.

Conceptually, I will frame my research using four concepts: First, students with disabilities are often viewed by higher education administrators as being a “drain” on resources, having less economic value than students without disabilities; second, all students have a right to equal opportunities through *access*. In my discussion, to have *access* is the ability to obtain or make use of all the services and opportunities enjoyed by students without disabilities as part of campus life and the educational experience. Third, the “ultimate value of [diagnostic testing and] documentation,”<sup>14</sup> is to give students a deeper understanding of themselves as learners, by understanding the implications of their diagnosis; and lastly, self-advocacy, which is the ability to assert one’s self in spite of opposition, actively pursuing the understanding of individual rights, and expressing individual needs and rights.<sup>15</sup>

I. I WILL BE DISCUSSING some background and justification for this research and three of my main findings:

Approximately 15 percent of the U.S. population has some type of learning disability, and one in seven children receive special education services due to their LDs.<sup>16</sup> The number of students with LDs that pursue post-secondary education is steadily rising due to more advanced assistive technology and better neurological understanding.<sup>17</sup>

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14 Skinner, Michael E.. “Promoting Self-Advocacy Among College Students with Learning Disabilities.” *Intervention in School and Clinic* 33, no. 5 (1998): 278-283. <http://isc.sagepub.com/content/33/5/278> (accessed February 19, 2012). 303

15 Skinner, Michael E.. “Promoting Self-Advocacy Among College Students with Learning Disabilities.” *Intervention in School and Clinic* 33, no. 5 (1998): 278-283. <http://isc.sagepub.com/content/33/5/278> (accessed February 19, 2012). 279

16 Learning Disabilities Association of America. “Adults with Learning Disabilities: An Overview.” *Learning Disabilities Association of America*. [http://www.ldanatl.org/aboutld/adults/special\\_pop/adult\\_ld.asp](http://www.ldanatl.org/aboutld/adults/special_pop/adult_ld.asp) (accessed July 9, 2012).

17 Denhart, Hazel. “Deconstructing Barriers: Perceptions of Students Labeled with Learning Disabilities in Higher Education.” *Journal of Learning Disabilities* 41, no. 6 (2008): 483-497. <http://ldx.sagepub.com/content/41/6/483> (accessed January 11, 2012). 483

Unfortunately, despite the increases in entrance, “the dropout rate for [students] labeled with LD remains high.”<sup>18</sup> People with LDs have historically been misunderstood as people who are stupid, lazy, slow or even “faking it.”

However, Thomas G. West and others have written extensively about the unrecognized and vastly underutilized strengths and talents of people with LDs.<sup>19</sup> It is common for people with LDs to have the ability to visualize words and very abstract ideas in three-dimensional ways, finding patterns that other people do not. They are very creative and think “outside of the box.”<sup>20</sup> This lack of understanding has devastating social consequences. According to the Learning Disability Association of America, 35 percent of students identified with learning disabilities drop out of high school. This is twice the rate of their non-disabled peers; 60 percent of adults with severe literacy problems have previously undiagnosed learning disabilities; 59 percent of females with learning disabilities will be mothers (many of them single) 3-5 years out of high school; and as many as 65 percent of the youth in juvenile correctional facilities are found to be eligible for special education services.<sup>21</sup>

**II. MY FIRST MAJOR FINDING** is the difference in regulation between K-12 and post-secondary education:

Public policy operates very differently between K-12 and post-secondary education. Unlike K-12, which is regulated by the Department of Education, there is no regulation in higher education institutions, or a “process aimed at achieving success.”<sup>22</sup> Post-secondary schools are

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18 Denhart, Hazel. “Deconstructing Barriers: Perceptions of Students Labeled with Learning Disabilities in Higher Education.” *Journal of Learning Disabilities* 41, no. 6 (2008): 483-497. <http://ldx.sagepub.com/content/41/6/483> (accessed January 11, 2012).

19 West, Thomas G.. *In the mind's eye: visual thinkers, gifted people with dyslexia and other learning difficulties, computer images, and the ironies of creativity*. Updated ed. Amherst, N.Y.: Prometheus Books, 1997.

20 Wolf, Maryanne. *Proust and the squid: the story and science of the reading brain*. New York, NY: HarperCollins, 2007. 200

21 Learning Disabilities Association of America. “Learning Disabilities and Low Income Populations.” *Learning Disabilities Association of America*. [http://www.ldanatl.org/aboutld/adults/special\\_pop/low\\_income.asp](http://www.ldanatl.org/aboutld/adults/special_pop/low_income.asp) (accessed July 9, 2012)

22 Wolanin, Thomas R., and Patricia E. Steele. “Higher Education Opportunities for Students with Disabilities: A Primer for Policy Makers.” *The Institute for Higher Education Policy* (2004). viii <http://www.transitiontocollege.net/resources.html> (accessed June 2, 2012).

governed only by the Office of Civil Rights who respond in a reactionary way only when a student files a legal claim that their rights have been violated. Thus, institutions are able to individually set guidelines and processes<sup>23</sup> that reflect their individual goals and culture.

**III. MY SECOND MAJOR FINDING** focuses on the attitudes often held by education administration within higher education:

As post-secondary institutions compete for resources and prestigious faculty, it is also necessary to attract students with the most academic promise. It is expected that these students will go on to be the leaders and innovators of the future, creating academic esteem, additional revenue through alliances, and donations for the institutions in the future. Thus, budgetary resource allocation is a critical part of the administrations risk/benefit decisions.

During my interviews, I was informed that within many college campuses, disabled student services are often seen as high-risk departments with low return value, but are necessary due to anti-discrimination laws. The term “loss-leader” was used to describe the perceived economic value of the disabled student population. That is to say, that resource allocations for this population are based on a non-income generating *compliance* model verses a revenue generating *investment*.

Quoting one of my interviewees who is a senior staff member at one of the participating universities,

“At my former job I was told, don’t go out and talk about disabled student services to the community. We’re just going to have more students with disabilities coming in. It’s a ‘loss-leader.’ Keep a low profile; hide and wait till they come in the door. That permeates the culture of these offices who are under severe pressures by administrators and their supervisors to control costs; now they’re torn between what the law says and their bosses who are on site telling them to control costs.”

It is clear that these students are not students who are viewed as becoming the leaders and innovators of the future.

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23 Madaus, Joseph W., Manju Banjeree, and Elizabeth C. Hambelt. “Learning Disability Documentation Decision Making at the Postsecondary Level.” *Career Development for Exceptional Individuals* 33, no. 2 (2010): 68-79. <http://cde.sagepub.com/content/33/2/68> (accessed February 19, 2012). 70

With equal *access* in mind, students with disabilities are provided support services and classroom (environmental) “adjustments.”<sup>24</sup> In order to obtain these support services, a student must prove they have an LD through the documentation process. It is here that a mechanism for cost cutting can be employed.

One would think that this documentation process is unique to the LD population due to its invisibility, but according to an interview with one of my participants, it is not.

“They can come in with a wheelchair or a guide dog and you’d still fold up your arms and say, ‘how do I know you have a disability?’ That kind of rigidity, almost passive aggressive behavior is illegal. The harder I make it for you to get into my program, the fewer of you are going to get in and I keep my costs down.”

Though having documentation is reasonable in order to aid the school in providing those services that would best help the student, it can be “overly-burdensome” and has profound effects on students.

#### IV. THIS BRINGS ME to the third portion of my findings:

Because testing requirements are different from one school to another, additional testing is often required. For instance, if a student has had testing done in grade school, in a junior college, or if the testing has been done three or more years prior,<sup>25</sup> it is standard practice that the student have new testing done to prove they still have a disability, even though current research supports that an LD is something that occurs across the life-span. Basic testing, according to an interview with one testing administrator, can start at twenty-five hundred dollars and go upward of four thousand dollars; students typically bare these costs.<sup>26</sup>

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24 McGuire, Joan M., Joseph W. Madaus, A. Vivienne Litt, and Michele O. Ramirez. “An Investigation of Documentation Submitted by University Students to Verify Their Learning Disabilities.” *Journal of Learning Disabilities* 29, no. 3 (1996): 297-304. <http://ldx.sagepub.com/content/29/3/297> (accessed February 17, 2012). 298

25 Madaus, Joseph W., Manju Banjeree, and Elizabeth C. Hambelt. “Learning Disability Documentation Decision Making at the Postsecondary Level.” *Career Development for Exceptional Individuals* 33, no. 2 (2010): 68-79. <http://cde.sagepub.com/content/33/2/68> (accessed February 19, 2012).

26 Students with Disabilities: A Primer for Policy Makers. “*The Institute for Higher Education Policy* (2004). <http://www.transitiontocollege.net/resources.html> (accessed June 2, 2012). 37

This adds a tremendous financial burden on a student, especially if they are from an impoverished background.<sup>27</sup> I argue that this burden can significantly decrease some student's opportunities to get into a school of their preference, despite the fact that they have already proven themselves academically capable. Then, if a student wants to go to graduate school the barriers can become even bigger.

#### V. WHERE DOES SELF-ADVOCACY PLAY into all of this?

If we accept that the “ultimate value of [diagnostic testing and] documentation,”<sup>28</sup> is to give students a deeper understanding of themselves as a learner by understanding the implications of their diagnosis, the question is then, do they? Do students understand their diagnoses? All of my interviews with learning specialists said that very few students were aware of the actual tests that were used to diagnose them. One specialist said, “In my experience students have very little awareness. They know they have been tested, [but] they don't understand the tests, per se.” Not only do very few students know what tests were administered, all specialists said that only 50 percent of students understand their diagnosis and are able to articulate it to others. In addition, few students know what their legal rights are. One of my interviews stated,

“It is not until a well-informed student understands they have rights and knows where to go to exercise them [that any change can happen for that student]. Most students at most schools don't. It takes a very savvy student to know their rights and push for them.”

While these students do learn differently than in the traditional classroom structure, if provided with environmental classroom adjustments and auxiliary aids such as books on tape, the classroom and learning process becomes one that can be productive and yield positive outcomes.

In conclusion, I argue that one aspect as to why these students do not understand their testing and diagnosis is because the primary focus is

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27 Wolanin, Thomas R., and Patricia E. Steele. “Higher Education Opportunities for Students with Disabilities: A Primer for Policy Makers.” *The Institute for Higher Education Policy* (2004). <http://www.transitiontocollege.net/resources.html> (accessed June 2, 2012). 37

28 Skinner, Michael E.. “Promoting Self-Advocacy Among College Students with Learning Disabilities.” *Intervention in School and Clinic* 33, no. 5 (1998): 278-283. <http://isc.sagepub.com/content/33/5/278> (accessed February 19, 2012). 303

not on fully understanding their diagnosis. Rather, it is to breakthrough the barrier of an overly burdensome documentation process to simply get the needed resources. In addition, I argue that most students do not understand their rights as a person who is considered by law to have a “disability,” thus lowering the possibility of self-advocacy.

It is here that I would like to offer a new paradigm, one that moves from a population that is seen as a “drain”<sup>29</sup> on resources to a value added population. To do so will open up new possibilities for minds that are incredibly talented and creative.

The aim of this research is to gain a deeper understanding of how diagnostic testing affects self-advocacy by hearing the “voices” of students who continually find barriers to success. While this research hopes that it will inform the general public about this issue, ultimately it seeks to assist students in gaining a better understanding of the situation in an effort for *them* to be the ones who breakdown the barriers. Thus, creating pathways for themselves and others that do indeed, have the *ability* to live successful lives and contribute to the future of our nation.

I will end with a quote by Stephen Jay Gould, “I am somehow less interested in the weight and convolutions of Einstein’s brain than in the near certainty that people of equal talent have lived and died in cotton fields and sweatshops.”<sup>30</sup>

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