

The Universal Design of Positive Identity Development For Disabled Students

Kelly Coons

Harvard Graduate School of Education

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Junlei Li

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Figure 1: Theory of Change for Disability Cultural Centers In Four-Year Higher Education Institutions.

Assumptions	Inputs	Mechanisms	Activities	Outputs	Outcomes	Impact
<p>A bachelor's degree grants upwards mobility and is a viable route to the middle class.</p> <p>Disabled people are not "college-material."</p> <p>When people see people like them in a position, they are more likely to try that role and persist there despite difficulties.</p>	<p>Trained, caring facilitator.</p> <p>Private, accessible discussion space.</p> <p>Knowledge of disability histories and cultures.</p>	<p>Development of positive identity.</p> <p>Erikson's theory of psychosocial development: preventing role confusion and replacing inferiority with industry.</p> <p>Self-efficacy.</p> <p>Zone of Proximal Development.</p>	<p>Social model of disability.</p> <p>Peer support groups.</p> <p>Education about disability history.</p> <p>Celebration of disability cultures.</p>	<p>Reduced isolation in disabled college students.</p> <p>Positive sense of disability identity.</p>	<p>Students self-advocating more.</p> <p>More students that can act in a mentorship role.</p> <p>Students are more likely to stay in college and obtain a bachelor's degree.</p>	<p>Higher expectations for disabled students in higher education as a result of more disabled students self-advocating and getting bachelor's degrees.</p> <p>More representation of disabled people in higher education and in various sectors of the workforce, including ones that require postsecondary education.</p>

College is an imperfect road to the middle class, but it is nevertheless a route that exists. Despite the cost of obtaining a Bachelor's degree, people with that degree can make enough money after graduation to recoup that cost—then make a profit. Immediately after graduation, the typical person with a Bachelor's degree makes, on average, \$21,000 more than the average person whose highest educational attainment is a high school degree (American Academy of Arts and Sciences' Commission on the Future of Undergraduate Education, 2016, 47). Over a working life, this difference in earnings is calculated to be about \$570,000 as the gap between pay for senior positions for those with a high school diploma or equivalent and those with a baccalaureate degree widens (Greenstone et al., 2016, 16). This type of upwards mobility is otherwise extremely difficult to achieve in the United States: a country characterized by its lack of government-funded social safety nets, especially as “good jobs”—a term coined by Georgetown University's Center on Education and the Workforce to describe jobs that pay a wage that can sustain a nuclear family—increasingly require higher education. Two out of three family-sustaining jobs require some kind of training from beyond high school, and more than half require at least a Bachelor's degree (Fischer, 2019). However, if college is a road to the middle class, it is a rocky one: 40% of college students drop out (Strauss, 2022), and the debt they accrue puts them in a more financially-precarious situation than if they had never gone to college at all. Disabled people are at a heightened risk of living in poverty, not only because of ableism on its own but because of how expensive essential healthcare such as mobility aids and medication are in the United States, where expensive and time-consuming diagnosis is both the prerequisite to accessing care and not a system that acts as a shield against predatory price-gauging. This risk of poverty is reflected in quantitative data as well: Disabled people are 11.4% more likely to live in poverty than their non-disabled peers, and the disabled poverty rate in the

United States is just over one-fourth (2020 Annual Disability Statistics Compendium). Even though a “good job” can be the ticket to a disability-sustaining wage, however, disabled people are underrepresented in higher education: “In 2019, 16.1 percent of people with disabilities had a Bachelor’s degree or more, compared to 39.2 percent of their peers without disabilities, reflecting a college-or-more gap of 23.1 percentage points (2020 Annual Disability Statistics Compendium).

Keeping in mind how essential a college degree can be for self-sufficiency, the gestalt low college completion rate takes on an increased layer of urgency for disabled people. College completion rates vary by type of institution: Full-time, first-time undergraduate completion rate at 150% time, which is the standard by which college completion is measured by the United States government, is at 68% at private non-profit 4-year institutions, 63% at public non-profit 4-year institutions, 29% at private for-profit institutions, and 34%—48% if you count transferring to another institution as a success—at public non-profit 2-year institutions (NCES, 2022). This is logical, although sad: Private non-profit institutions have a larger budget per student than do public non-profit two-year institutions, also known as community colleges. However, even within the same college or university, college completion rates vary wildly depending on the demographics of the student! David Kirp, author of *The College Dropout Scandal*, warns, “The graduation rate for black and Latino students, and students receiving Pell grants [federal grants for low-income students] is 10 to 20 percent lower [in comparison to the overall graduation rate]” (Strauss, 2022). Focusing in on the college completion rate for disabled people, for first-time, full-time, “traditionally aged” college students, meaning ages 18 to 23, disabled people have a 34% completion rate (Saia, 2022, 17). This is illogical and infuriating: Students at the

same institution are in the same classes, with the same faculty given the same professional development. How can we remedy this injustice?

I believe that the principles of universal design, a movement pioneered in disability spaces, can help guide programming for all marginalized students to help equalize the college graduation rate at institutions across the higher education sector. Universal design argues that creating a system to serve the most vulnerable also increases the quality of that system for everyone. To that end, I want to argue on behalf of the creation of disability cultural centers at all higher education institutions, or at least an informal space to discuss the experience of disability in all college spaces and integrate it into intersectional movements of equity and justice.

All people feel the need to develop a distinct identity for themselves. Erik Erikson, the founder of the psychosocial theory of development, lists the need to develop an identity as the fifth of life's "crises": the struggle between establishing a place for yourself and role confusion (Erikson, 1968). Erikson characterized this as the challenge of adolescence, although it is fair to say that this challenge extends beyond that timeframe and can be returned to later in life as well. Adolescence is the time in a person's life between feeling innately satisfied with the information that loved ones give us and having settled into ideas about how the world does and should work. Thus, it is a time when people are developmentally primed to explore new perspectives. Erikson articulates how this exploration cannot be done alone. He also explains the benefits of having established an identity for oneself: It "...promotes self-confidence, facilitates decision-making, and provides the foundation for fulfilling interpersonal relationships" (Erikson, 1968). Later theorists, like Mandy Savitz-Romer and Suzanne M. Bouffard, brought in Erikson's theory of psychosocial development into the context of the college search process, talking about how students of various backgrounds develop a "college-going" identity or not (Savitz-Romer &

Bouffard, 2012, 64). They discussed a particular subject, “Kamilah,” who assumed that, because she had received special education services, she could not go to college (Savitz-Romer & Bouffard, 2012, 77). This episode illustrates how developing a “college-going”—and “college-staying”—identity is more difficult for students with marginalized identities, one of which is ability status.

Black sociologist W.E.B. DuBois coined the term “double consciousness” to describe the difficulty Black Americans had in reconciling their racial and national identities, as “Americanness” is equated with whiteness and Blackness is associated with Africa (DuBois, 1897), which many Black Americans, including DuBois, had no trackable tie back to. In the interest of not appropriating that experience, which I do not share, I will instead use terminology articulated by the professional coach of educators Elena Aguilar to discuss my own lived experience: internal identity, how you see yourself, and external identity, how the society you live in sees you (Aguilar, 2021). I am Autistic. (I am using identity-first language, capitalizing my neurotype to reclaim its importance to my sense of self, rather than the person-first language that is dominant in the larger cultural lexicon, which posits that people should be seen as “people first” because I believe that, even with invisible disabilities like autism, that axis of difference is quickly discovered, or at least inferred, and used to otherize. By saying it first, I am taking that moment of discovery for myself and not letting misinformation proliferate in my social interactions. This is not something that is universal among disabled people, but it is something that I am doing and want to name.) That is something that has been true about me all my life. I was born Autistic, and I will die Autistic. However, I did not always know this about myself. I was not diagnosed until age 13. Thus, as a child, I thought I was neurotypical, like the statistical majority of people are. My internal identity was that I was smart: I received high grades in

school, and I was well-liked by my teachers. My external identity, on the other hand, and how I was viewed by my peers in particular, was that I was “weird” and that my academic success could not possibly be due to my own ability—because it was proven that I wasn’t “smart” enough to understand what they were saying—but was in fact because I was a “kiss-up” to the adults around me. This disconnect between my internal and external identity was painful and confusing, and I felt like because they were opposites, one of them had to be a lie. During my late elementary school years and into my time in middle school, certainly influenced by my acceptance into the district’s gifted and talented program, I decided that the external identity was a lie. In an attempt to construct congruence between my internal sense of competence and external labeling of incompetence, I decided that my peers were incompetent and the things that I did not understand, like what clothes were “in,” were in fact frivolous and thus not things I even needed to learn. Once I was diagnosed—and told about my diagnosis, which was not something my father wanted to do because he did not want me to feel “limited”—I revisited my internal and external identities. I still believed that I was smart, but I decided, armed with this new information, that my peers weren’t “stupid.” They actually saw the world in a very different way than I did and were competent in that context: the context of neurotypicality that was the dominant discourse and would remain that way, so, far from being free to ignore them, I had to work extra hard to understand because I would never be playing in my “home field.” This vignette from my life corroborates Savitz-Romer's and Bouffard’s findings that “...when youth develop and maintain confidence in their abilities and positive attitudes about their cultural and racial backgrounds, they are more likely to have high academic achievement, positive future orientations, a strong self-concept, psychological well-being, and the ability to cope with and respond to discrimination” (Savitz-Romer & Bouffard, 2012, 80).

However, my experience, in which I retained a positive sense of self, is in fact uncommon among disabled people. The system through which disabled people are schooled once they are diagnosed—which is, again, a prerequisite to receiving services that are essential to grasping the content that is provided, from sign language interpreters to one-on-one aides to help one navigate the school landscape—operates on separating disabled students from their peers, if not through physical separation, like my younger brother’s special education classroom being in the dark basement of his high school, then through the issuing of alternative assignments. Little effort is made to help disabled students, especially those with learning disabilities, work with their neurotypical and able-bodied classmates. To put it another way, special education is a normalized form of tracking. The special education “track” is not the college “track.” My younger brother is also Autistic, and he has several comorbid disabilities as well, including an anxiety disorder, ADHD, and intellectual disability. Diagnosed with these disabilities in early childhood, his schooling experience has always been through the institution of special education. In high school, the parents of youth like my younger brother in my district are presented with two options: to attempt to keep up with coursework or to pivot towards life skills, sometimes from outside of the public school system. These two options are not presented as equal. The “academic” route is presented as a series of diminishing returns, whereas the “life skills” program is presented as the last chance to mold useful behavior—never mind that providing access to postsecondary education for intellectually-disabled people from ages 18 to 21 is required under Connecticut state law. My mother fought to keep my younger brother on track for a high school diploma: something she was only able to do because of her knowledge of disability law and her status as a stay-at-home mother, so she could commit to being a watchdog full-time. The school did not share her vigilance. Come sophomore year, my younger brother started

receiving emails about college events, and he was interested. He wanted to be like everybody else. Being like everybody else included taking the SAT. Most colleges require applicants to take a standardized test like the SAT. My brother and mother expressed interest in the SAT at the IEP (individualized education plan) meeting, and the school balked: They had never had a student in special education take the SAT before! Where were they going to get a paraprofessional to stay for the duration of the test!? What would he even get out of it anyway!? Is it any wonder, with reactions like this from people in positions of institutional power, then, that disabled people like Kamilah decide that they are not “college material”?

How do we support the disabled people who make their way to four-year institutions, despite the structural and societal messaging obscuring that path? Fortunately, there is a robust body of data about how to increase college graduation rates, and one of the major concepts among that collection of work, helping people feel a sense of belonging, applies equally to disabled people.

In his psychosocial theory of development, Erik Erikson describes the need to develop one’s own identity as one of life’s crises (Erikson, 1968). Erikson also articulates the benefits of developing an identity, calling it a crucial component of healthy development which “...promotes self-confidence, facilitates decision-making, and provides the foundation for fulfilling interpersonal relationships” (Erikson, 1968). The component of self-confidence is especially important for disabled people, who, before entering college, have been inundated with explicit and implicit ableist messaging about how their disabilities, which they cannot control, must be overcome. In other words, disabled people are told that their natural states are inadequate to fulfill the dreams they have. Erikson calls identity versus role confusion the fifth of life’s crises, but, before that situation can be addressed, as a result of this pervasive ableism, for disabled

people, the fourth of life's crises, taking place during their interactions with the PK-12 educational system, is likely to have resolved in an unhealthy way, with a sense of inferiority becoming dominant over a sense of industry—also known as a sense of self-efficacy.

There are four components to self-efficacy: performance accomplishment (experience of achievement), vicarious experience (seeing someone else act), verbal persuasion, and physiological states (stress versus calmness; Bandura, 1977, 191). Stimuli do not affect behavior simply by virtue of happening at the same time or happening directly afterwards. Not only must a connection between behavior and result be clearly communicated, but that relationship must be repeatedly reiterated. To feel good about something, it is not enough for a person to do it. People can view the result as the exception to the rule or as the result of outside intervention, rather than the product of their own efforts. As a result, even though seeing someone else do something is less likely to reassure a person that they can do the same, it can often be the first step in being willing to try. Seeing someone else try something is especially encouraging if the observer sees similarities between themselves and the model (Bandura, 1977, 202). There can be no gains in self-efficacy if a person is not willing to try the thing that they believe they are not good at, so building up a feeling of being safe to try and potentially fail is essential.

Affinity spaces on college campuses provide a place where people similar to each other can interact and test their abilities, and disability cultural centers are simply another kind of affinity space. Affinity spaces are valuable because they help people with marginalized identities protect against their views of themselves, their internal identities (Aguilar, 2021), being subsumed by the dominant, often degrading, view of people from the majority, in-power groups. For example, disabled students at the University of Arizona reported low expectations of them by faculty and peers (Saia, 2022, 18), nonconsensual use as inspirational material (Saia, 2022,

21), and shock at their very presence (Saia, 2022, 21). Over time, these views can affect how a person views themselves and their capabilities, and even for those who maintain a positive view of themselves, even people with a strong sense of self-efficacy can give up if they feel that their environment is hostile to their efforts or unresponsive to them (Bandura, 1977, 205). Thus, a place where disabled people can be seen as people before they are seen as their disabilities can be a healing environment. Such a place can be calming, and calming environments are particularly conducive to developing self-efficacy, for high arousal interferes with reasoning skills (Bandura, 1977, 198).

Yet disability spaces are not usually depicted as affinity spaces. Consider where disability services offices are. At my alma mater, Smith College, the disability services office is across from the registrar's office: Disability was an administrative affair. At University of Arizona, the disability services office, called the disability resource office, is within campus health (Saia, 2022, 23), situating it as a medical matter to recover from with accommodations (or, depending on how ableist the environment is, through "hard work" and "not making excuses"). In neither of these cases are disability services offices near campus affinity spaces. The participants in the study, while praising the new disability cultural center, highlighting how it was a place for them to be free of pity and staring (Saia, 2022, 24), how it helped them see their bodyminds (a term from disability studies that rejects mind-body duality) as something they can be proud of (Saia, 2022, 26), how it connected them to hitherto-unknown history of disability activism and culture (Saia, 2022, 26), nonetheless noted that it was treated differently than other cultural centers on campus, being on the outskirts of campus, hidden, not in the student union building (Saia, 2022, 27).

Disability cultural centers, as affinity spaces, counter the dominant narrative that both disabled and non-disabled people are told about disability: It is a legal entity to be managed, rather than a legitimate part of a person's identity to be honored (Saia, 2022, 19). Moreover, it helps disabled people see themselves as part of a community, rather than a singularity. Learning about disability history provides more alike models for myriad careers and advocacy work. Learning about disability culture helps people integrate disability into pre-existing and pre-lauded values about the importance of respecting diversity. Disability cultural centers can even teach a paradigm about disability that moves the onus of change from disabled individuals towards society as the disabling component: the social model of disability. The social model of disability argues that disability is not caused by bodies and minds but by the lack of accommodation for those differences (Saia, 2022, 19). However, these sites of sorely-needed inclusion are rare. There are only 10 disability cultural centers in higher education institutions in the United States as of January 2022 (Herder, 2022).

Disability cultural centers are not only a site of cultural and civic engagement either. Academic learning is itself a social process and is assisted through having access to trusted peers. Lev Vygotsky, in the creation of his theory of the Zone of Proximal Development, specifically used the example of the education of disabled people to highlight how his model was a departure from the normative understanding of how knowledge is gained: "The actual developmental level characterizes mental development retrospectively, while the zone of proximal development characterizes mental development prospectively" (Vygotsky, 1978, 86-87). The Zone of Proximal Development argues that people have an ever-evolving range of potential skills and that instruction should be targeted in the space between what a person can accomplish on their own and what they can do with help from another person. This theory slots in perfectly with

Albert Bandura's figuring of the development of self-efficacy as a social process. Bandura emphasized that people were most supported in their sense of competency when they felt like their guide was similar to them, so having someone similar to them act as a guide in academic work is equally especially helpful.

A disability cultural center gives disabled college students access to similar peers and a body of knowledge about the accomplishments of past people like them. As a result, they should feel an increased ability to self-advocate. In addition, they are more likely to feel able to act as a guide to other people, regardless of their ability status or their setting, because even though the increases in self-efficacy are the largest with similar skills to the one(s) focused on gaining self-efficacy in one domain or setting nonetheless assists in the development and maintenance of a transferrable, universal sense of self-efficacy (Bandura, 1977, 195). As their sense of belonging increases, so should their motivation to stay in college and complete their degrees. As students and professionals in higher education take notice of individual successes, they are more likely to hold higher expectations for disabled people in the future, even if they do not formally learn about disabled history or disabled culture from events hosted by the disability cultural center or from people who attended such events. As it is understood and communicated that disabled people can in fact be "college-material," more disabled people are likely to be attracted to postsecondary education and thus be able to act as living, breathing representatives in higher education and in the many jobs that require postsecondary education in a society where connections have an "outsized role" (Baum & McPherson, 2022, 13) in career attainment and movement. The impact of disability cultural centers reaches beyond the doors, windows, and halls of campuses and may one day be a part of the disability history lessons taught in such facilities in the future.

Works Cited

- Aguilar, E. (2021). Exploring identity markers. In *The Art of Coaching Workbook*. Newark: John Wiley & Sons.
- American Academy of Arts and Sciences' Commission on the Future of Undergraduate Education. (2016). *A Primer on the College Student Journey*.
<https://www.amacad.org/publication/primer-college-student-journey>.
- Bandura, A. (1977). Self-efficacy: Toward a unifying theory of behavioral change. *Psychological Review*, 84, 191-215.
- Bois, W. E. B. D. (1897, August 1). *Strivings of the Negro People*. The Atlantic.
<https://www.theatlantic.com/magazine/archive/1897/08/strivings-of-the-negro-people/305446/>.
- Erikson, E. H. (1968). *Identity: Youth and crisis*. NY: Norton.
- Fischer, K. (2019, December 30). *Why Higher Ed's Promise Remains Unfulfilled*. The Chronicle of Higher Education. Retrieved from <https://www-chronicle-com.ezp-prod1.hul.harvard.edu/article/why-higher-ed-rsquo-s-promise-remains-unfulfilled/>.
- Greenstone, M; Looney, A; Patashnik, J; Yu, M (18 November 2016). "Thirteen Economic Facts about Social Mobility and the Role of Education". Brookings Institution. <https://www-proquest-com.ezp-prod1.hul.harvard.edu/docview/1792585093?pq-origsite=primo>.
- Herder, L. (2022, Jan 27). *Only Ten Disability Cultural Centers Exist at U.S. Institutions*. Diverse: Issues In Higher Education.
<https://www.diverseeducation.com/demographics/disabilities/article/15287582/only-ten-disability-cultural-centers-exist-at-us-institutions>
- Mandy Savitz-Romer and Suzanne M. Bouffard (2012). *Ready, Willing, and Able: A Developmental Approach to College Access and Success*. Chapter 1: More Youth, More Ready: A Developmental Understanding of Gaps in Educational Equity (pp 23-40)

<http://ezp-prod1.hul.harvard.edu/login?url=https://search.ebscohost.com/login.aspx?direct=true&db=nlebk&AN=1168921&site=ehost-live&scope=site>

The NCES Fast Facts Tool provides quick answers to many education questions (National Center for Education Statistics). (n.d.). National Center for Education Statistics. Retrieved October 6, 2022, from <https://nces.ed.gov/fastfacts/display.asp?id=40>.

Saia, T. (2022). Disability Cultural Centers in Higher Education: A Shift Beyond Compliance to Disability Culture and Disability Identity *Journal of Postsecondary Education and Disability*, 35(1), 17-30.

Sandy Baum and Michael McPherson (2022). Introduction. In *Can College Level the Playing Field? Higher Education in an Unequal Society* (pp. 1-22). Princeton University Press.

Strauss, V. (2022, Sept 16) *Perspective | 'A dereliction of duty': The college dropout scandal — and how to fix it.* (n.d.). Washington Post. Retrieved from <http://www.washingtonpost.com/education/2019/09/10/a-dereliction-duty-college-dropout-scandal-how-fix-it/>.

2020 Annual Disability Statistics Compendium | Annual Disability Statistics Compendium (National Institute on Disability). Retrieved September 28, 2022, from <https://disabilitycompendium.org/compendium/2020-annual-disability-statistics-compendium>.

Vygotsky (1978). Interaction between Learning and Development. *Mind in Society*. pp. 79-91. <https://ebookcentral-proquest-com.ezp-prod1.hul.harvard.edu/lib/harvard-ebooks/reader.action?docID=3301299&ppg=94>.