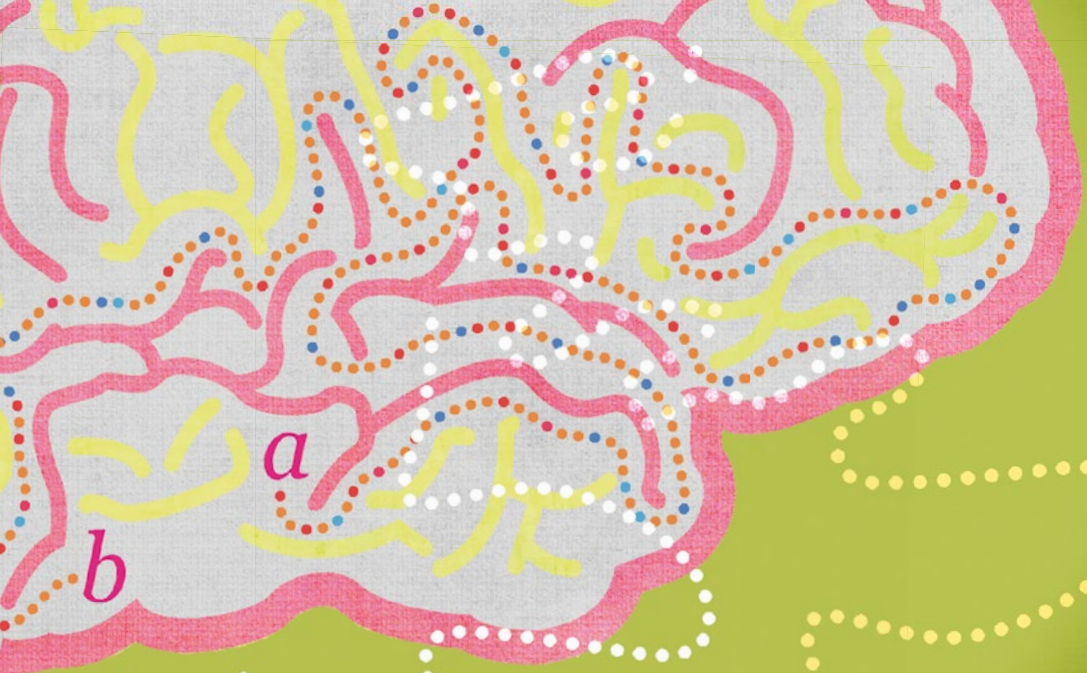

Dana Lee Baker +
Brandon Leonard

NEUROETHICS IN HIGHER EDUCATION POLICY

Neuroethics in Higher Education Policy

Dana Lee Baker • Brandon Leonard

Neuroethics in Higher Education Policy

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For Karen Schmaling, with gratitude, for all the walks and wisdom
And for Laurie Drapela, who makes both of our lives better.

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Contents

CHAPTER 1

Neuroethics and Higher Education

Higher education exists to elevate humanity. Colleges and universities work to prepare students for enhanced participation in the economy, culture, society, and political system in which they reside. Higher education also aims to provide students with the capacity to create and make good use of the ever-expanding knowledge, skills, and abilities underpinning advancement of complex societies. If for no other reason, diversity rests at the core of contemporary higher education since it is key to the strength of sophisticated societies. Without diversity, higher education does not exist as such.

In North America, higher education started as a vehicle for a greater understanding of human knowledge and principles of faith. During the nineteenth century, its purposes began to expand more to applied training, especially in the land-grant colleges. The twentieth century ushered in professionalization, a focus on research, and expansion of access through both increased student density and proliferation of campuses (Eaton 2014). Thus far, the twenty-first century continued the digital expansion of access, growing tension between research and corporatization, and overall reduction of state support for public education, combined with expressed concerns about the overall cost to the student (Milheim 2013; Zumeta 2010).

The meaning of diversity evolves. Defining diversity at the beginning of the twenty-first century incorporates many identifiers, caveats, and explanations. Diversity involves contested space, even among its strongest proponents and becomes easily confounded with both individual identities

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and discourses of oppression, particularly in regard to instances where social and individual justice interact. In the context of public policy, diversity refers primarily to reversing **systemic oppressions** deeply embedded in all modern democracies, and a reinvented commitment to keeping the republic through an emphasis on strengths involved incorporation of difference into human endeavors. Baseline definitions, such as the list of immutable characteristics found in the **Office of Equal Opportunity** policy statements, have consistently expanded (Pfeffer 2014; Wallace and King 2013). As of 2016, the list provided by the US Equal Opportunity Commission includes age, disability, genetic information, national origin, pregnancy, race/color, religion, and sex (U.S. Equal Employment 2016). While such guidelines are crucial to both representativeness and inclusion, diversity is not linearly defined and instead exists on a spectrum that, once articulated, contradicts its own intent. Diversity means difference and difference implies a commitment to change.

Higher education in the United States of America embraces a commitment to diversity, at least in principle. However, advances in neuroscience and changes in attitudes toward disability have identified mechanisms by which higher education infrastructures diminish students' capacity to enter, persist, and complete higher education. Often, but not always, such challenges are associated with neurological difference, whether identified or not. Much work remains to be done to enhance inclusion of neurological difference in higher education. A **neuroethical** approach to higher education precludes systematic exclusion. This book explores neuroethics and **neurodiversity** in higher education in the United States of America. After introducing readers to the philosophical and policy foundations of the neuroethics of higher education, this book explores essential conundrums in the neuroethical practice of higher education in modern democracies. Current higher education policy and access programs underestimate the effect of ill-fitting infrastructures on those considered neurologically typical (Markoulakis and Kirsh 2013; Salzer 2012). Many of the policies also serve to unnecessarily stratify the student body through identification requirements and the design of accommodations or infrastructures. As a result, neuroethical gaps abound in higher education.

Language of Disability

In considering neuroethics of neurodiversity, language of disability becomes complicated. Until recently, most disability scholars, activists, and stakeholders in support of greater inclusion of disability in society favored

person first language (Prizant and Fields-Meyer 2015). This language was adopted for two primary purposes. First, as the name suggests, proponents of this language form asserted that when thinking about difference, remembering that every person is a person first holds primary importance. Second, disability came to be understood as including different capacity differences depending on the era, socioeconomic circumstances, and political environment in which a person existed. Given this understanding of disability, personhood always precedes disability.

In recent years, **issue stakeholders**, especially disability activists, have increasingly questioned the habitual use of person first language (Prizant and Fields-Meyer 2015). These concerns are not entirely novel. Jim Sinclair wrote in 1999 about his concerns about people first language tied to the fact that it perpetuates existing perceptions that disability is both shameful and separate from an individual's core identity. As Sinclair explained:

> I can be separated from things that are not part of me, and I am still be the same person…I am usually a "person with a purple shirt," but I could also be a "person with a blue shirt" one day, and a "person with a yellow shirt" the next day, and I would still be the same person, because my clothing is not part of me…But autism is part of me…Autism is hard-wired into the ways my brain works. I am autistic because I cannot be separated from how my brain works (1999, 1).

Arguably, questions about the construction of identity hold particular relevance for young people and people undertaking deliberate self-transformation, making concerns about the language of disability particularly pertinent to higher education. As Shattuck et al. describe, "identity refers to one's self-image and has multiple facets including racial and ethnic identity, gender identity, and disability identity…identity formation is a dynamic, nuanced, multidimensional, and lifelong process that takes on particular importance during emerging adulthood when questions about life purpose and direction move to the foreground" (2014, 1). The place of disability in each identity will likely differ and, especially during early adulthood, fluctuate. Difference in identity construction depends not only on individual preference but also to intersectional identity characteristics, whether a disability is acquired or innate and a society's contemporary response to a given difference. The ethical principle of respect for **autonomy** includes an individualized conception of autonomy. **Nonmalfeasance** also demands responsible handling of the regretful circumstance that implications of highlighting disabilities vary by

the nature (and, too often, name) of the difference. Space and time constraints preclude listing all permutations of identity in a comprehensible discussion. Given this, in this book, both person first and disability first language are employed, at times together and where appropriate, independently. Use of this language embraces both the strengths and imperfections in all facets of current discourse.

Diversity in Higher Education

Increased transparency of **inclusion** of neurological difference on college and university campuses creates a responsibility to consider the philosophical and policy implications of neuroethics in higher education. Education across differences in capacity is governed in primary and secondary education under *The Individuals with Disabilities Education Act* (IDEA). First created as the *Education for All Handicapped Children Act* in 1975 (PL-94-142), IDEA establishes a positive right to free and appropriate education in the least restrictive environment to children identified as having a disability (Janiga and Costenbader 2002). However, higher education across differences in capacity is governed primarily under the *Americans with Disabilities Act* which focuses more exclusively on remediating discriminatory practices and infrastructure and Section 504 of the *Rehabilitation Act* (Denhart 2008). Some of the differences contributing to neurodiversity are routinely identified as disabilities. Other differences in capacity exist outside the continuum of recognized disabilities or formal diagnosis (Denhart 2008; Manthey et al. 2015; Ness and Vroman 2014; Sarrett 2016). In this text, an inclusive definition of neurological difference encompassing both recognized diagnoses included in the fifth edition of the *Diagnostic and Statistical Manual* and those with more emergent characteristics yet to be fully vetted by the academy is employed unless otherwise specified.

Rights-based disability movements began with an emphasis on physical disability (Shakespeare 2013). Early successes in public policy involved requiring changes and accommodations in physical infrastructure. Exclusion of people on the basis of physical characteristics still happens all too frequently in higher education, and work on this injustice must continue. For example, despite the routine presence of ramps on university campuses, their placement often reflects insufficient consideration of the utility of those ramps for daily users on campus (Armstrong 2012; Baker 2011). Even so, exclusion of people with neurological differences or

mental health concerns involves not only design challenges similar to those associated with physical accessibility but is also hindered by less developed understandings of how to practice inclusion even in the best circumstances and with unlimited resources (Gidley et al. 2010). Furthermore, not all stakeholders agree that people with neurological differences or mental health belong on college and university campuses. Articulated justifications for such discrimination and exclusion include biases about the intellectual capacities of people with neurological differences and a belief that a neurological difference makes a person dangerous to others (Scior 2011). Disability is not fully recognized as a form of diversity on the majority of campuses in North America and is more often than not excluded from lists of personal characteristics associated with diversity upon which the college or university focuses diversity efforts (Banks 2016; Rendon 1994; Shallish 2015). Neurodiversity is even less routinely valued than other forms of disability in higher education, in part because of misconceptions about essential relationships between neurotypicality, intelligence, and potential.

Neurodiversity refers to the belief that neurological variation naturally exists in all populations. As a natural aspect of the human condition, the mere presence of difference implies nothing beyond difference. The term originated with autistics but in recent years has expanded to include the full gamut of neurological and behavioral differences such as Attention-Deficit/Hyperactivity Disorder (ADHD), bipolar disorder, and schizophrenia (Armstrong 2012; Silberman and Biech 2015). One of the earliest known references to neurodiversity in print was by an Australian mother of a child on the autism spectrum, Judy Singer (Solomon 2008). Though the concept depends on the body–brain division modern neuroscience has repeatedly demonstrated illusory, our sense of self in Western society still embraces the brain as distinct enough from the body and physical function to make neurodiversity a necessary field of study beyond disability diversity in general.

Neurodiversity also describes a social and political movement, one of the rights movements that have characterized the twentieth and twenty-first centuries. The advancements in disability rights have been staged in their progression similar to feminism and other civil rights movements tied to particular identifying characteristics (Woodhams and Danieli 2000; Shapiro 1994a). Neurodiversity as a social and political movement was initially both lead and defined by autistic adults (Denhart 2008; Baker 2011). Many of the initial efforts of the movement were coordinated and conducted online to create advances for neurologically different people similar to what feminism and gay rights movements had done for their

respective populations. Locating initial efforts online reflected the communication preferences and lack of geographic proximity between founding leaders, and the era in which the movement came about.

Focal points of the neurodiversity movement included reclaiming the human rights and civil liberties of those who have been diagnosed with neurological differences, redefining neurological differences as positive elements of human identity, for both individuals and groups, and reasserting the **constructivist** understandings of disabilities. The goals of this movement required more than accommodations to existing infrastructures allowing for the participation despite neurological difference while still favoring the infrastructure preferences of people considered neurologically typical. The degree to which individuals with neurological differences, including autism, have been historically denied their rights is still largely unrecognized by society at large (Silberman and Biech 2015). By the second decade of the twentieth century, the neurodiversity movement, like the definition of neurodiversity as a human condition, expanded to also include the interests of those identified as having other neurological differences. For example, during the fall of 2015, Ari Ne'eman, a leader of the neurodiversity movement in the USA, publicly criticized discourse surrounding mass shootings for too-frequently scapegoating people who are diagnosed with mental illnesses (Pitney 2015).

Enhancing neurodiversity on campuses arguably involves an even more nuanced approach to remediation, restoration, and inclusion than is the case for other forms of diversity. Neurological disability is often difficult to detect with initial contact, especially if casual. Often characterized as **invisible disability**, such ways of being are incompatible with intuitive, adaptive models commonly employed by public programs and other provisions established by the *Americans with Disabilities Act* and provided for under Section 504 of the *Rehabilitation Act* (Shakespeare 2014). Voluntary identification as a person with a disability in higher education is required for disability-related educational services. Similarly, ADA complaints or lawsuits are not filed anonymously.

The model for disability services in higher education differs from the special education required under the *Individuals with Disabilities Education Act* (IDEA) which obligates schools to make efforts to identify eligible children. The Individualized Education Plan requirement under IDEA (ideally) includes provisions for a personalized, holistic, and developmental plan as opposed to simply a series of accommodations considered necessary for a particular course or activity as articulated under

ADA and Section 504 (Janiga and Costenbader 2002; Myers et al. 2014). This distinction is of particular relevance for neurodiversity and the neuroethics of higher education more generally. Brains continuously adapt to environments. College course structures and expectations in a program of study in higher education vary alongside both academic discipline and professors' teaching styles. These factors interact to create dynamic barriers to access and participation in higher education for students with neurological differences and neurodiverse students.

Disability involves **social construction**. This conception means that disability exists only when limitations of the flexibility of surrounding infrastructures intersect with the limitations in the capacity of the individual with the difference to stress their capacities to suit the prevailing infrastructures of their social infrastructures. It is useful to consider capacity differences through a taxonomy reflecting the interaction between the infrastructures and the individual. It is also useful to highlight which public policy strategies tend to prove most effective as counterweights to tendencies toward exclusion of individuals with disabilities and disabled people (Baker 2011). In recognition of the social, political, and economic progress of the last five years, the **taxonomy** employed in this book includes an additional category of difference, in which the difference is transformed into an identity rooted in pride in difference.

In seeking to understand the nature of neurodiversity and in enhancing neuroethics, it is important to understand that there are five basic ways in which capacity can diverge from that which is considered typical within a given society: difference (an atypicality considered irrelevant or ignored by the given society); impairments (a difference considered relevant but not a hindrance to daily life functions or participation in a given society); disability (an impairment understood as limiting daily life functions of the person); handicap (a disability understood as inherently connected to lower socioeconomic status (SES) in the surrounding society). In twenty-first-century America, another category of atypicalilty has increasingly gained attention, disabled. Disabled differs from disability (or having a disability) in that it considers the condition as a positive element of identity, regardless of where the momentary implications of the difference fall on the handicap, disability, impairment, difference continuum. In other words, from the disabled perspective, an atypical capacity is a point of pride, nearly exclusively so long as it is not connected with essential decline in overall health (i.e. a disease). This changes the balance of where flexibility is anticipated to be both possible and necessary. It also

brings into question the very principle of daily life functions, at least those outside of necessities attached to daily survival. Finally, it calls into question the sufficiency of accommodations designed primarily to allow for participation in a world and its infrastructures still built almost exclusively in accordance with the preferences of the neurological majority.

The position that an atypicality takes in the capacity continuum described above depends on the intersection of the social infrastructures and the policy interventions designed to mediate the effects of their insufficient flexibility. The medical model of understanding specific characteristics as inherently disabling is premised upon the acceptance of a singular preferred from existence in the world (Prizant and Fields-Meyer 2015). The model is described as medical not necessarily because of its exclusive or predominant use by physicians. It is also not medical in the sense that without health care intervention or treatment, the individual would become sick or die. Rather, it refers to the understanding that (negative) outcomes of difference are predominantly or exclusively the result of characteristics of an individual's mind, body, or choices. There is, archetypically, little to no consideration of the role of surrounding infrastructures on implications of characteristics. Under the medical model, for example, a fish laying on the sidewalk would be considered to be disabled or handicapped because it is incapable of performing the requirements of daily life based on its physical characteristics; when in fact, the potential for the fish to be of a superior design in a different environment exists. Other conceptions of disability, such as the social models of disability, consider the interaction between the individual and the environment as the location of disability. When an environment can be transformed or made more flexible, many characteristics that are considered disabilities can be transitioned to differences. The inability to move without an electric wheelchair may be disabling in a House of Escher, but exchanging stairs for ramps may eliminate any restrictions. This potential creates a greater significance to the language used to identify individuals with disabilities and disabled individuals.

In understanding social construction, it is important to keep in mind the category in which individuals experiencing atypicality in a particular human capacity find themselves in this taxonomy can vary from moment to moment and from infrastructure to infrastructure. Different forms of public policy move atypical capacities along the continuum from handicap to disabled. To mediate the effects of handicaps, human and civil rights policies must be established. In other words, a person must be understood as a person of the same status as other humans in order to avoid handicap.