

**Making disability visible in higher education research: Documenting qualitative,
quantitative and theoretical issues and solutions**

A report submitted to the Spencer Foundation by:

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Introduction

Between May 30 and June 1, 2018, nineteen scholars and two graduate students from across the country convened for an intensive conference titled Making Disability Visible in Higher Education Research: Addressing Quantitative, Qualitative, and Theoretical Limitations. One of the goals of the workshop was to: “document the issues (and potential solutions for) the measurement limitations (qualitative, quantitative, theoretical) related to the study of college students with disabilities.” In order to achieve this goal, we (the organizers and participants), engaged in some pre-conference reflections on these topics. In April 2018, we contributed our initial ideas about challenges and solutions on a Google form. Results from the Google form were compiled into a word document and used as a foundation for intensive conference conversations about issues and solutions in higher education disability research. (See Appendix A).

At the conference, we divided into three small working groups that focused on theoretical scholarship, quantitative research, and qualitative research. These working groups discussed the issues and solutions listed on the pre-conference Google form along with additional ideas generated via face-to-face conversations. On day two of the conference, our working groups came to consensus about what we believed were the 5-6 most pressing issues related to theoretical, quantitative, or qualitative scholarship on disability in higher education. In the following pages, we summarize the results of our collective work.

THEORETICAL RESEARCH

In our discussions, we focused on one central question: What is disability? Notably, in our discussions, we did not consider that question to be either a problem or a solution. Instead, it became clear that the question related to both possible problems and solutions.

Issue 1

Disability is a multivalent construct and is not always clearly defined in published work.

Potential Solution 1

Researchers should consider some or all of the following issues when designing research projects and reporting study findings: 1) their overarching understanding of disability (e.g., social, environmental, social justice models); 2) their expectations for how findings might be used (e.g., to structure one-on-one interactions, as part of a universal design for learning intervention); 3) the specific disability types and/or diagnoses represented in the study (e.g., mental health conditions vs. generalized anxiety disorders, learning disabilities vs. traumatic brain injuries); 4) the extent to which a disability is readily apparent or easily hidden in social settings (i.e., the distinction in existing literature between visible and invisible disabilities); 5) the inclusion and/or recruitment criteria utilized (e.g., Prior IEP or Section 504 Plan, Accommodations via Disability

Services, Self-Definition, Variation in Experience); 6) the self-identification of study participants (e.g., many culturally Deaf and neurodiverse persons do not identify as people with disabilities; some people with disabilities identify with a specific diagnosis or do not consider themselves “disabled” enough to use the term; some students with disabilities eschew their disability diagnosis while in college); 7) whether students have been told they have a disability prior to college; and 8) the context for the research on disability.

Issue 2

Disability is a category of social identity but is under-theorized as such.

Potential Solution 2

Like many other categories of social identity, disability can be both an assigned label and also a part of the way that people with disabilities think about themselves. It is also a form of identity that is fluid over time in several critical ways: 1) social and environmental conditions can produce contexts that are more or less disabling, which may make a disability identity more or less salient; 2) many people with disabilities vary across the life course with regard to the degree to which they consider disability as an affirmative part of their self-understanding; 3) most forms of disability can occur at any point in the life course; 4) disability is experienced intersectionally; and 5) the way that people make meaning of the physiological and psychological dimensions of their disability. Using theoretical perspectives such as Crip Theory, DisCrit, and critical disability studies, researchers can undertake research explicitly focused on disability-as-identity and can also offer implications for understanding disability-as-identity drawn from non-identity focused work. A key feature of these perspectives, and also of thinking about disability as a form of identity, is the recognition of the prevalence of disability stigma, its role in the identities and identification decisions of people with disabilities, and its connection to oppressive ideologies of ableism and disableism.

Issue 3

The policy context for disability is inadequately addressed in existing work.

Potential Solution 3

Research should acknowledge the broader ecological system within which the experiences of people with disabilities reside. Notably, there is a substantial gulf between the way that federal policy shapes response to and measurement of disability in K-12 and higher education settings. Further, inadequate government support for people with disabilities also means that the people’s experiences of disability are structured by inequitable access to needed diagnosis, services, and resources, which is stratified by social positionalities such as race, class, gender, and geography; research should acknowledge this variation in experience.

Issue 4

The goals of people with disabilities, higher education institutions, and policymakers may not be in alignment with one another.

Potential Solution 4

People access higher education for varied reasons. An understanding of those reasons is integral to a full representation of the postsecondary experiences of students with disabilities. Consistent with theoretical constructs such as autonomy, self-direction, self-determination, and self-advocacy, wherever possible researchers should seek to understand the postsecondary plans of students with disabilities and should provide interpretations of findings consistent with those plans. Where such data is not available, researchers should acknowledge potential interpretations that regard gaps in outcomes as arising in part from the deliberate, informed decisions of people with disabilities rather than from a failure to achieve in normative ways.

Issue 5

Research on postsecondary outcomes for students with disabilities has often focused on standard metrics of students success (e.g., persistence, four-year degree completion within four years). Although this work is needed, research on alternative educational trajectories as well as research revealing the points at which the educational trajectories of students with disabilities begin to diverge from those of students without disabilities is needed.

Potential Solution 5

Researchers should recognize the real pressure from policymakers, funding agencies, and higher education institutions to produce research that informs an understanding of timely four-year degree completion. In providing actionable empirical information that shapes this understanding, however, researchers also have an opportunity to produce work that helps broaden the understanding of outcomes for students with disabilities by: documenting other student success outcomes (e.g., two-year degree completion, completion of a four-year degree in more than four years, non-degree education leading to employment); demonstrating the points at which the educational trajectories of students with disabilities diverge from one another and/or from students without disabilities; and acknowledging the postsecondary outcomes for students with disabilities who do not attend college (e.g., workforce participation, the school-to-prison pipeline).

Issue 6

Findings related to disability need to reach graduate students, student affairs professionals, higher education administrators, and senior academic administrators who can benefit most from the insight offered therein.

Potential Solution 6

Findings need to be presented in multiple formats and venues accessible to the desired audiences, which can be accomplished via strategic publishing (e.g., journals, listservs, higher education news outlets) or via other professional development opportunities (e.g., workshops, conferences, webinars, courses). Articles related to disability in higher education are published in a relatively small number of journals, and with the exception of the Journal of Postsecondary Education and Disability, few appear in higher education specific journals (most frequently in the Journal of College Student Development, Community College Journal of Research and Practice, and Journal of Diversity in Higher Education). More work in additional venues is needed, but it has proven difficult to publish outside of specialist venues. Advocacy to editors and participation in editorial boards as reviewers by those with a background in disability in higher education is needed. Authorial decisions about how to contextualize this work can also help to reshape expectations: the importance of addressing the experiences of students with disabilities cannot be justified solely in numerical terms because their experiences are intrinsically important and those numbers are misleading. While this research is important, outreach via other dissemination venues should also be pursued. A critical part of this dissemination should be careful thought about graduate preparation and initial training (e.g., freestanding courses, as part of multicultural services or student development) and definitions of professional competence.

QUANTITATIVE RESEARCH

In our discussions, two central, connected, themes arose. First, how we construct and design research matters. Second, who is included within such designs and construction (and those who are excluded) also matters. We were unwilling to separate these two themes from one another due to the interconnected and interdependent relationship of how they inform one another.

Issue 1

There is a lack of a consistent definitions related to disability and/or classification system across data sources.

Potential Solution 1

Couched in the first theme of how we construct and design research, is the notion of a collective or consistent definition of disability across data sources. One potential solution to increase a seamless use of a consistent definition or classification system is to foster data sharing partnerships. Examples of such partnerships include but are not limited to cross-institutional data sources (consortium, database, repositories), within institutional data sources (ODS, faculty,

admissions, IR), and state-level longitudinal datasets. Within the state-level datasets, an intentional focus on crossing structural boundaries and including multiple data points for individual students (in single use design) could offer additional consistency within state and national longitudinal data collection.

Issue 2

Reliance on self-disclosure in the postsecondary world equates to only a portion of students with disabilities' voices included in the larger narrative of data.

Potential Solution 2

Data should include those who disclose to offices of disability services and those who choose not to. In an effort to increase those represented in our reporting, we should not rely solely on students who have disclosed. One way to intentionally include both those who disclose to an office of disability and access and those who do not would be to reorder survey instruments to include disability identifiers towards the conclusion of the instrument. In addition to an instrument redesign, transparency in the data collected is also necessary to more accurately report whose voice was included and whose experience was excluded. Far too often, findings from studies (and study design) are presented as an overarching, blanket statement for the experiences of all students with disabilities. Journal editors, editorial boards, and publishing companies possess a responsibility and an opportunity to shift the course of how data and methods are shared. Journal editors have the academic capital to shift the scope of expectations for authors and relay those specifications to reviewers and authors before research is published and disseminated into the world. With similar clout to hold researchers and authors accountable, editorial boards and peer reviewers are endowed with the obligation to encourage clarity in manuscripts submitted. Further, authors and researchers have the capability to provide thorough and detailed appendices or to push past word counts and page limitations with online supplements for published studies.

Issue 3

Narrow and limited research sites are considered in research designs and reported as reality for all, even those outside the scope of such limited environments.

Potential Solution 3

Often researchers and scholars design, digest, and reiterate seemingly general data, but that has been designed with narrowly defined environments. Thus, what the field of higher education is left to assume is that studies and findings from traditional college and university settings is the gold standard. In reality, significant portions of higher education do not fit that criteria. Instead, higher education is a diverse landscape of learners who are both traditional, post-traditional, on campus and online, and attend institutions in the postsecondary world that include a swath of

characteristics. Some postsecondary educational environments are technical or trade type institutions while others are traditional brick and mortar learning environments. Researchers should of course focus an intentional effort on transparency to report such characteristics of data, but we should also find mechanisms to no longer exclude institutions outside the scope of traditional postsecondary educational environments. One such way would be to gather a collective of scholars and practitioners from the diverse facets of higher education to develop guidelines or recommendations for designing research and reporting data and findings. Another way to incorporate the vast array of institutions is to encourage a transferrable application across various arenas within implication sections of manuscripts.

Issue 4

A variety of intertwined factors (e.g. relatively infrequent occurrence of specific disabilities, HIPPA and FERPA laws that limit data sharing, student reluctance to self-disclose) can make it difficult for researchers studying college students with disabilities to find large, diverse, or representative samples for their studies, thereby limiting both explanatory power and practical value.

Potential Solution 4

Ideally, issues related to sampling would be addressed first at the design stage of research, with intentional efforts like a priori power analysis or targeted oversampling to generate appropriate samples. Studies focused on low-occurrence disabilities or those that use repeated measures to evaluate the effectiveness of individual interventions may wish to consider single-case designs. Studies addressing characteristics, experiences, or outcomes for groups of students (e.g., students with autism or students with limited mobility) may find quasi-experimental designs involving instrumental variables or propensity score matching allow for statistical comparisons between different student populations or permits evaluation of effectiveness for specific interventions. Additionally, studies employing more traditional correlation and regression-based analyses could use advanced methods to address missing data (e.g. multiple imputation [MI] or full information maximum likelihood [FIML]) in ways that maximize sample size and minimize sample bias. Finally, researchers ought to consider measuring disability in a way that goes beyond the binary disabled/not-disabled to surface the underlying factors that may describe the manner in which one's disability are manifest in their lived experiences.

Issue 5

Implicit reinforcement of and a reliance on deficit base understandings of disability or medical models of disability.

Potential Solution 5

More often than not, researchers, both quantitative and qualitative, rely on medical models of disability. This reliance reinforces deficit understandings of disability and places responsibility upon an individual, participant, or student, to seek inclusion within research or accommodations and services in postsecondary environments. Instead, what might serve as a more inclusive design practice is to enact participatory methods prior to study design or instrument construction, to more authentically capture how participants define or frame disability in their own lived experiences. Further, engagement of participatory methods beyond study design or instrument construction might also include an on-going cycle of survey development, pilot testing, revisions, interviews and focus groups, revisions, and any follow up.

QUALITATIVE RESEARCH

In our discussions, we focused on a variety of topics that we believe are central to conducting inclusive, ethical, and effective qualitative research on disability topics in higher education. We drew upon a micro-lens to address day-to-day decisions made by scholars as well as a macro-lens when discussing how qualitative research should be framed by theory, informed by the disability community, and immediately applicable to policy and practice.

Issue 1

Research often uses deficit lenses and/or sees disabled people as the “problem.”

Potential Solution 1

One of the ways to address this issue is for scholars to engage in self-reflection about their perspectives and positionality. Do they see the research “problem” through an ableist lens? Do they see participants through a deficit lens? Scholars must engage candid reflections on the ways they envision a “problem” and design research questions in ways that may portray disabled people as the problem or non-normative. One strategy for addressing deficit perspectives is for scholars to name ableism and explicate how it influences their work. Moreover, scholarship can move away from portraying disabled people via a deficit by examining disabling environments as part of the research process. For instance, the lived experiences of college students with disabilities should be examined in the context of disabling policies, inaccessible settings, ableist organizational structures, and unwelcoming climates.

Issue 2

Navigating the need/press to study groups of people with disabilities in the aggregate (for political, fiscal reasons) versus focusing on the richness of nuance of different disabilities.

Potential Solution 2

The first step to addressing this issue is determining *if* your question is best answered by aggregating people with different disabilities into a broad category of students with disabilities. Or, is the research question best answered by focusing on samples of people with particular disabilities? As part of the decision making process, scholars should weigh the benefits and drawbacks of each approach. Then, scholars should select an appropriate method and data

collection approach that will result in an in-depth study of the aggregate (e.g., grounded theory) or people with specific disabilities (e.g., narrative analysis). Another consideration when thinking about delving into the nuance of disability is examining diversity *within* specific disabilities and/or by exploring intersections of disability with other social identities.

Issue 3

Implications for practice, policy, and future research often place the onus of responsibility for change on people with disabilities, reinforce stereotypes, and are not always relevant to various audiences.

Potential Solution 3

Scholars must take precautions not to frame implications in ways that reinforce stereotypes and/or deficit perspectives about people with disabilities. One of the common ways this happens is by placing the onus for change on disabled people versus questioning or challenging disabling policies, programs, or services. As such, scholars must take care in contextualizing study findings in ways that specify institutional responsibility for change. Moreover, scholars must not frame findings/implications as reifying “normal”--which reinforces ableist worldviews. Finally, scholars should ensure that implications for practice, policy, and future research are relevant for various audiences (e.g., disability services, faculty, administrators, funders, policy makers, people with disabilities, K-12 educators). This requires using audience specific language and obtaining feedback from multiple audiences before publishing findings.

Issue 4

Research processes often fail to include the perspectives of disabled people (even though they may be the focus of a study) or input from the disability community.

Potential Solution 4

Scholars should view disabled people as collaborators rather than subjects or participants in a study. Such perspectives can lead to reciprocal relationships between researchers and the disability community as well as mutually beneficial outcomes. The disability community should be included in every aspect of research process. For instance, the community (not the researcher in isolation) should identify if there is a problem to study, the research questions that should be asked, and the most effective and inclusive methods for data collection, and the drafting of practical recommendations that meet community needs. A researcher should always consider: What are the interests and priorities of the community? Researchers also need to find balance in getting direct input from the disability community without being tokenizing or exploiting people with disabilities. Other strategies that can be used to more fully include disabled people into the research process include: 1.) using language/terminology that honors participant meaning making and evolving identities and 2.) working at a pace needed by participants versus the pace and expectations in academe.

Issue 5

Research is either not theoretically grounded or presents theories in a way that is not understandable.

Potential Solution 5

Higher education scholars must use, construct, and advance theories that can be used in qualitative disability research. One hallmark of effective qualitative research is firm grounding in theoretical frameworks. When scholars fail to situate their work in a theoretical framework, quality suffers. The onus is on scholars to explore the many theories available and to be thoughtful about selecting theories that do not reinforce the oppression of disabled people. Critical and liberatory theories are especially useful for informing disability research as they inherently challenge deficit notions of people with disabilities as a problem. Instead, such theories offer scholars useful tools to critique oppressive systems and foreground agency of participants. Finally, scholars must take care in explaining complex theoretical frameworks (e.g., crip theory) in a manner that is accessible, clear, and understandable for a broad range of audiences. When audience members read research steeped in unnecessarily complex academic language, it can be inaccessible to the very community members who could benefit most from those studies.

Issue 6

Disability scholarship is steeped in whiteness.

Potential Solution 6

Disability research has long been synonymous with whiteness. Both research participants and disability scholars themselves are disproportionately white. This issue requires a two pronged approach. First, the scholarly community cannot be satisfied with the overwhelmingly white researcher lenses used to shape the cannon of disability research in higher education. As such, the higher education community needs to mentor, recognize, and promote scholars of color doing disability research. Scholars of color must be considered as valuable knowledge creators on this topic. Second, scholars must be intentional about recruiting racially diverse samples so that we can better understand disability-related higher education phenomena. Without including the experiences and worldviews of racially diverse samples, research conclusions are exclusionary and incomplete. As such, scholars should not be satisfied with claiming lack of racial diversity as a sampling limitation. Instead, scholars must be intentional about using purposive sampling strategies to locate and recruit racially diverse participants.

Appendix A

MAKING DISABILITY VISIBLE WORKSHOP Pre-Conference Survey Results Issues and Possible Solutions

Issue	Possible Solution to Issue
Studies that treat all students with disabilities as one large lump, implying sameness in experience when there are very clearly massive differences.	Don't do the binary variable in qual studies. Look at your data in quant coding differently. Ask students how they describe their world rather than employing external labels.
Failure to recognize co-occurrence and the complexity associated with this.	Include co-occurrence in data analysis. Understand why using "other" as a category is a problematic from a critical perspective.
Who counts as a person with a disability?	Acknowledging that disability is a multivalent construct, we need to be clearer what we mean when we use the term-- in design, recruitment, analysis, interpretation, and dissemination activities.
How do we handle the environmental manifestation of disability?	We need to examine how people may experience their disability differently in different places on campus (e.g., classrooms vs. residence halls, internships vs. research opportunities).
The lack of available data on students with disabilities. Institutions are very reluctant to release this information even in aggregate form.	In my opinion, a solution would be for higher education institutions to collect and report data on students with disabilities. Disability status should be seen as just one more demographic item.
The reluctance of higher education students to disclose having a disability.	We need to find a way to destigmatize the identification/disclosure of a disability. Students (especially veterans) are often reluctant to report having a disability or request accommodations.

<p>Investigating ableism and the higher education environment, beyond student experiences related to disability that may unintentionally reinforce individualized notions of disability</p>	<p>Research that addresses policy, governance, culture, norms of able-bodiedness/mindedness in higher education with student experiences as one (but not the sole) piece of the puzzle</p>
<p>Studying specific populations of students with disabilities AND students with disabilities as an umbrella group or coalition with some shared experiences and obstacles</p>	<p>Increased researcher/community reflection on the benefits and drawbacks of studies that take a coalitional/umbrella approach and/or that utilize specific populations, diagnoses, experiences</p>
<p>Continuing to state a lack of diversity as a limitation</p>	<p>We have to expand and diversify our participant pools and work together across states to more accurately recruit, collect data, and represent folks with disabilities in higher education. It is not socially justice or appropriate to continue producing all White disability work.</p>
<p>Clumping all folks with disabilities into single studies</p>	<p>Support, encourage and produce more disability specific work.</p>

<p>In most higher education studies, student samples are not representative of most students with disabilities enrolled in higher education. When students with disabilities, who are identified by their high school as having a disability, continue their education, only 35% choose to disclose that disability to their postsecondary school; leaving 65% of the population of postsecondary students with disabilities “under the radar” of most studies. Additionally, those who do disclose tend to have more visible disabilities, than do the full population of students with disabilities.</p>	<p>More longitudinal studies that follow students from high school, where their disability is identified by their school, into postsecondary school, so that samples includes the broader population of those with disabilities.</p>
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<p>Two additional issues related to student samples: 1. Experiences of students with disabilities vary widely by disability category—often there’s greater variation across students in the various disability categories than between students with disabilities as a whole and their peers in the general population. 2. Approximately one- third of young adults with disabilities enroll in career/technical education (CTE) schools; however, these types of schools are almost completely ignored in postsecondary research, where the focus primarily is on 2- and/or 4-year colleges.</p>	<p>1. All studies should clearly consider during the sampling stage whether and how to focus the samples to include only students with specific types of disabilities. Additionally, it’s important for all reporting to document the types of disabilities of students included research samples. 2. More attention needs to be given to experiences and outcomes of students with disabilities in CTE schools.</p>
<p>sample size of students with disabilities (esp. various types of disability for within-group comparison)</p>	<p>I am still struggling to identify an appropriate dataset</p>

comparison of student engagement between students with disabilities and non-disabled students	Recently NSSE started collecting the variable of disability.
To what degree can disaggregating data reinforce a deficit narrative?	Consider data sources and reporting language.
How can other theoretical models (beyond the medical model) be used to ask students about their disability?	Examine best practices from fields other than higher education.
Developing established Universal Research Design principles.	Use this workshop as a space to discuss and conceptualize ways to build onto and strengthen existing knowledge about URD principles.

We need more research that is useful and practical to helping institutions of higher education support students. We need more research that informs higher education policy about students with disabilities.	Engage in workshop discussions about designing research that has real implications to inform institutional, state, and federal policy.
How to measure disability in surveys?	Find multiple agreed upon ways to do this, that are aligned with frameworks and models that are appropriate.
Availability of data for students with low-incidence disabilities in particular (avoiding very small samples for quant work)	Urge more data collection for these needs (e.g., the next NLTS? other NCES surveys take oversamples?)

Limited amount of evidence based research; limited descriptions of samples, methods	Development of research guidelines
Limited publication outlets for research; higher education journals (in general) publish very little on this topic	Collaboration/discussion with journal editors and with professional organizations
We tend to focus assessment and research on diagnostic categories or impairments, rather than the design that disables individuals, which perpetuates a medical or charity approach to disability, rather than sociopolitical. It continues to frame individuals as problematic, expensive, needy, etc.	Use Universal Design and the Social Model as our theoretical frameworks and do research on how design necessitates accommodations.

While we tout the benefits of UD on campus access (increasing inclusion in instruction, events, policy, etc.) there is a lack of empirical research on the impact of UD on learning, engagement, retention, budget.	Research how UD contributes to inclusion, retention, success and positively impacts teaching/faculty perceptions of disabled students.
Most disability services educators have as their advanced degree the master's degree. They are practitioners, not researchers. Few of them have doctoral degrees, which most often means that they have very little training in research methodology.	Encourage disability services educators to partner with faculty members on their campuses to explore research-related topics on their campuses.
Most of the literature reports on data from single-site institutions.	Encourage collaboration across campuses. Provide research funding for multi-campus research projects.

Predictive funding to support each students accommodation related needs	A national matrix that examines each student's unique demographic/disability and averages the funding profile for a student taking into regional financial impact considerations.
The impact of disability positive identity in academic persistence and completion.	Develop a self-actualization framework pilot with a cohort model that tracks measurements of student success
The aggregation of disabilities within a diverse identity	Focusing research on particular aspects of disability (although this "solution" has its limitations)
Limited intersectional/critical research	Efforts to conduct more research using critical theoretical perspectives

Research Participants - Hard to find adequate number of participants, especially with regard to specific or "hidden" disabilities; selection bias, participants are typically those who are comfortable with identity and disclosure;	Partnerships with outside agencies (e.g., state agency for persons with disabilities, local school systems, Voc Rehab) and collaboration across institutions
Definitions and Intersectionality. Changing terminology, multiple definitions, overlap between conditions, and intersecting identities make it difficult to differentiate the effects of component identities or disabilities.	"select all that apply" is likely better than limiting people to a single checkbox; using definitions consistent with grounding frameworks or paradigms (i.e., not always relying on the government or DSM or definitions.