

A Disability Studies Framework for Policy Activism in Postsecondary Education

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Abstract

This article uses disability studies and the social model of disability as theoretical foundations for policy activism in postsecondary education. The social model is discussed and a model for policy activism is described. A case study of how disability studies and policy activism can be applied is provided utilizing the “3C Project to Provide Students with Disabilities a Quality Higher Education,” a federally-funded development grant.”

A Disability Studies Framework For Policy Activism in Postsecondary Education

Disability studies (DS) is an interdisciplinary area of study that situates disability at the center of the humanities, sciences, social sciences, and applied fields of study. Disability studies “challenges the view of disability as an individual deficit or defect that can be remediated solely through...intervention by ‘experts’ and other service providers” (Society for Disability Studies [SDS], 2004). The applied field of Disability Studies in Education (DSE) holds to tenets consistent with those identified by the Society for Disability Studies (above). More specifically, DSE aims to

- contextualize disability within political and social spheres;
- privilege the interests, agendas, and voices of people labeled with disability;
- disabled people;
- promote social justice, equitable and inclusive educational opportunities, and full and meaningful access to all aspects of society for people labeled with disability/disabled people; and
- assume competence and reject deficit models of disability (Connor, Gabel, Gallagher, & Morton, 2008, p. 448).

While specific guidelines or tenets have been identified, “neither Disability Studies nor Disability Studies in Education represents a unitary perspective” (Taylor, 2006, p. xiii). However, scholars of disability studies

agree that disability is a social construct (Connor, et al., 2008, p. 447), accordingly, “disability is not a ‘thing’ or condition people have, but instead [it is] a social negation serving powerful ideological commitments and political aims” (ibid.). The proposition that disability is socially constructed by the enactment of ideology and political aims is often referred to as the “social model of disability.”

Social Model of Disability

Multiple versions of the social model exist in the literature. The oldest, a neo-Marxist version, is sometimes referred to as the “strong social model” (Shakespeare & Watson, 2001). It differentiates between impairment or functional limitations experienced by an individual, and disability or the marginalization and even oppression of people with impairments as a group. This strong social model critiques the structural and institutional barriers that prevent people with impairments from full participation in all aspects of society (Priestly, 1998). This places disability as located “squarely within society” rather than in individuals. Furthermore, as to whether impairment or functional limitation of some kind is addressed in this model:

it is not individual limitations, of whatever kind, which are the cause of the problem but society’s failure to provide appropriate services and adequately ensure the needs of disabled people are fully taken into account in its social organization (Oliver, 1996, p. 32).

Oliver was influenced by the Disabled People's Movement in the United Kingdom and the publication of the *Fundamental Principles of Disability* by the Union of the Physically Impaired Against Segregation ([UPIAS], 1975).

Oliver is speaking to what Priestly (1998) has described as the “material product of socio-economic relations developing within a specific historical context” (p. 78). Priestly positions this as a realist account where the “units of analysis are disabling barriers and material relations of power” (ibid.). The strong social model's materialism sometimes is described as a reductionist account that ignores the interactions between individuals and society and, in fact, disability studies scholars have criticized it for this and other reasons (Gabel & Peters, 2004; Shakespeare & Watson, 2001). However, the strong social model is a useful framework for strategic action in policy because it clearly focuses attention on the institutional structures that disable people by putting up barriers to full inclusion.

Priestly (1998) describes another form of the social model of disability as the social constructionist model in which disability is the “product of specific cultural conditions,” or the “product of societal development within a specific cultural context” (p. 81) where “the units of analysis are cultural values and representation” (p. 78). In other words, culture at-large constructs disability through what is held to be true about normalcy and how truth is represented in cultural symbols, practices, and rituals. Cultural symbols that affect disabled people include disability stereotypes and visual representations. For example, the stereotype of disabled people as weak and incapable can lead to the view of disabled students as “watering down the college curriculum.” Cultural practices include policies, procedures, and traditions that lead to segregation and social isolation. For example, technology policies inattentive to access issues thereby excluding some students from information systems, procedures for obtaining accommodations that require students to self-identify and that may increase the stigma associated with impairment, or the tradition of postsecondary education as a meritocracy that historically has excluded disabled people from entry. Cultural rituals can also disable people. For example, rituals of standardized testing that serve as mechanisms for gate-keeping into postsecondary programs, and rituals of testing and assessment that may label disabled students who have been admitted to a program as “not meeting program standards.”

Applying DS framework to postsecondary policy work

The two versions of the social model of disability discussed in the previous section—the material with an emphasis on socio-economic factors and the cultural with an emphasis on symbolism, representation, and value—are useful in postsecondary policy work that aims to address the institutional structures that can disable people. Material structures can be understood as those that are designed to provide resources and/or support to students, for example, scholarships, loans, tutoring, library books and articles, and of course accessible built environments. Cultural structures, the values, symbols, and representations infused throughout the postsecondary milieu, are those underlying frameworks and assumptions that influence behavior, discourse, policy, and practice. Examples of cultural structures include institutional marketing materials (e.g., who is depicted as a student at the institution?), mission statements (e.g., are access or diversity included and if so, how are they understood and enacted?), and admission and retention policies (e.g., what are the gatekeeping devices and who do those devices exclude?).

Examples from the 3C Project

Examples from a federally funded development grant—the 3C Project—can be useful in understanding the applications of disability studies to postsecondary policy activism, or policy work that has social justice aims. As an introduction, I briefly describe the 3C Project (funded by US Department of Education Office of Postsecondary Education grant #P333A080036), whose purpose is to provide a quality higher education to students with disabilities. The 3C Project at National-Louis University (NLU) in Chicago, Illinois, aims to create a model for institution-wide change in access and inclusion for students with disabilities. The three Cs represent the project's policy foci. *Context* refers to three contexts of teaching and learning: contexts internal and external to the university, contexts that are both face-to-face and virtual, and contexts that are local and national. *Content* refers to three types of content knowledge needed to provide students with a quality education: technological content, practical content, and theoretical content. *Culture* refers to a culture of inclusion for which all community members are responsible. The culture of inclusion entails creating visibility, accessibility, and possibility. In sum, the 3C Project provides support and professional development for administration, faculty,

and staff to improve their ability to: (1) provide and facilitate contexts that support learning, (2) make content accessible to all learners, and (3) create a culture of inclusion. While it is necessary to involve students in creating a culture of inclusion, the social model of disability emphasizes the responsibility of society at large for dismantling barriers and creating inclusivity, so the 3C Project focuses on the responsibilities of university employees for creating an inclusive community.

Policy Model and Process Part I: Policy Streams

Part one of the model of policy activism (Gabel, 2008) is borrowed from Weiss' (1990) scholarship on policy advocacy, a concept of policy making structured by argumentation and political timing in what John Kingdon (2003) calls the "policy primeval soup" (p. 116), where ideas float around disconnected from problems or solutions. It is in this milieu that that ideas become prominent and then fade," "soften up," "confront one another and combine with one another in various ways" (Kingdon, 2003, pp. 116–117). The idea selection process, which leads to the development of new policy, depends on what Kingdon (2003) refers to as an *open policy window*, or that moment at which problems and potential solutions (or alternatives) convene with the political ripeness that creates opportunities for the policy worker to intervene, offer solutions, and influence change.

At the postsecondary level, the policy soup can start bubbling for a variety of reasons. At NLU, the policy soup started bubbling with the 2005 recommendation from education doctoral students (Becker, Kleish, & Stern, 2005) that the university should adopt a universal design (UD) or universal design for learning (UDL) model of supporting students with disabilities. From 2005–2008, Kingdon's notion of softening up of ideas as well as the confrontation and recombination of ideas was observed: (1) Education college faculty produced a White Paper (Gabel, German, & Wu, 2006) arguing for incorporating UDL into the college strategic plan, (2) online conversations (debates) among college faculty ensued, and (3) the college strategic planning committee included "access" in one of its goals while rejecting wording specific to UDL. Although the decision to avoid specific reference to UDL was disappointing to faculty supportive of the idea, the softening up process had begun and led to the submission of the OPE grant proposal in 2008.

Simultaneously, the University Diversity and Inclu-

sion Council began debating the meaning of diversity and eventually included "ability diversity" in its mission statement in 2008. This was the first time the university had defined diversity to include dis/ability.

Kingdon's (2003) is a policy model in which the primeval soup gives rise to three policy streams that run simultaneously and in parallel: (1) problems, (2) solutions or alternatives, and (3) politics (Figure 1). The *problems stream* is composed of those individuals or groups working toward identifying and defining problems or refining problems that have been identified by others. The *solutions or alternatives stream* is where solutions are actively created and made ready to combine with problems when the time is right, when a window opens. The third stream, the *political*, is composed of policy elites—for Kingdon, legislators and their aides, but in this case, higher level administrators and the Faculty Senate, which has some authority in policies affecting faculty and student learning. The streams represent a fluid and somewhat unpredictable model. When all three streams converge—the political atmosphere is just right, problems are clearly defined, and solutions are available and acceptable—consensus may emerge and policy may be shaped.

Problem stream. As discussed earlier, a problem had been identified in 2005 by doctoral students and subsequently by some faculty as the ineffectiveness or lack of use of campus disability services and the lack of faculty awareness of a UDL model. However, over the years, the problem came to be redefined by those involved in this initiative as multi-pronged and more complex, including, for example: (1) *contextual barriers*, such as inaccessibility and exclusion resulting from the well-intentioned but insufficient compliance model of service delivery at the institutional level (Cory, Taylor, Walker, & White, 2003), including insufficient resources to sustain the model (e.g., assistive technology); (2) *content barriers*, such as the lack of institutional knowledge of the percentage of disabled students it is serving and the subsequent inability to assess program effectiveness with disabled students; and (3) *cultural barriers* constituted through the construction of disabled people as invisible in the university community, leading to stigma, exclusion, isolation, and the inability of the university to be accountable for its work with disabled students.

Examples of the above barrier categories can demonstrate the depth and typicality of the problems. Within the compliance model (problem 1 above) the focus is on the "letter of the law" and regulatory policies but

while compliance might meet the “letter of the law,” it can be unsatisfactory on many levels (Burgstahler & Cory, 2008; Cory et al., 2003). The compliance model requires students to self-identify to receive disability accommodations. Many students avoid self-identifying for fear of stigma (Izzo, Murray, & Novak, 2008). Other students do not realize they have conditions that interfere with learning. At NLU, this is often the case with older students who have developed age-related conditions. Compliance models require students to qualify as disabled. Qualification often requires medical or psychological evaluations that can be expensive and time-consuming as well as disturbing or discouraging. Many students cannot afford these evaluations or avoid them for other reasons. Finally, compliance models do not account for the fact that many students struggle academically for reasons other than disability (e.g., cultural or linguistic differences) and only address the need for accommodation on a case by case basis without the view to an overall plan for inclusion (Izzo, et al., 2008). Consistent with these criticisms, prior to 2009, less than 1% of NLU’s students had self-identified as disabled using the university’s compliance procedures.

However, by 2009, 14% of NLU’s students identified as disabled via the ACCESS survey available from AHEAD (Vogel, 2008) and a survey the grant project entitled the “3C Student Census,” closing the gap on a content barrier (problem 2 above) at the university. These surveys collected important data, including the disability categories identified by students, college attendance, campus attendance (NLU has 5 Chicago area campuses), and other useful information.

As an open-access university, NLU’s history and student body lends itself to a learner-centered approach. However, as indicated in problem 3 above, prior to 2005, it was unclear whether faculty were aware of the historical increase in the number of students with disabilities attending institutions of postsecondary education. Faculty members from a variety of departments and disciplines often claim to have never had a student with a disability in the classroom, suggesting that faculty expected to be able to *see* whether or not disabled students were in their classes. The assumption that disability is visible is a content barrier (problem 2). Disabled people also have been invisible in the cultural artifacts of NLU—marketing materials and websites, for example.

Solution stream. Years ago, the small group of doctoral students concerned about these issues thought the solution would be to substitute UDL for the compli-

ance model. This was one of the aims of the 3C Project, however it is clear at this time that the solutions are much more complex than merely implementing a UDL model. One must remember that the process of institutionally defining problems and solutions is fluid and somewhat unpredictable. Faculty, staff, and student awareness of ableism (Hehir, 2002) and disability stereotypes (Davis & Watson, 2002) is needed, as are a recognition of the way barriers disable people, knowledge and skill in inclusive teaching through UDL or any framework designed for access that avoids retrofitting whenever possible, and the capacity to respond effectively to student needs for accommodation. The stigma of disability needs to be minimized so that disabled members of the learning community feel more comfortable openly identifying and sharing their experiences as opposed to answering questions on an anonymous survey. This can be assisted by creating visibility in the cultural artifacts produced by the university: websites, marketing materials, and the curriculum (e.g., history of the disability rights movement in history classes, contribution of disabled people to science, disability art in fine arts classes, etc.). Kingdon’s (2003) model suggests that these solutions need to be well considered and ready for an open policy window. However, at this university as at other large institutions, policy windows are influenced by the politics that percolate in the political stream.

Political stream. At the postsecondary level, the political stream includes a variety of local actors, including faculty leaders (department heads and senior faculty), college administrators (Deans), university administrators (Provost, Vice Presidents, President), and the Board of Trustees who are the ultimate policy elites of the university.

The political stream operates at international, national, state, and local levels. The importance and value of higher education for a broad spectrum of the world’s population has been on the international agenda for over a decade. *The World Declaration on Higher Education* (United Nations Educational, Scientific and Cultural Organization [UNESCO], 1998) argues that “education is a fundamental pillar of human rights, democracy, sustainable development and peace” and that “the solution of [sic] the problems faced on the eve of the twenty-first century will be determined . . . by the role that is assigned to education in general and to higher education in particular” (Preamble, ¶ 5). Article 3 of the Declaration addresses equity of access, stating that “no discrimination can be accepted in granting

access to higher education” and that “access to higher education for members of some special target groups,” including disabled people according to the Declaration, “must be actively facilitated” with “special material help and educational solutions” that “can help overcome the obstacles that these groups face, both in accessing and in continuing higher education.”

At the state level, the Illinois Board of Higher Education’s (IBHE, 2007) blueprint directing state policies and resources to higher education very specifically speaks to the issues raised in this case. The IBHE’s (2007) *Public Agenda for Illinois Higher Education* found

a tale of two states of Illinois. One is prosperous; the other is struggling. One is well educated; the other lags in educational attainment. One is economically vibrant; the other is economically stagnant. Between these two states is a prosperity gap that is wide and growing and the direct result of disparities in educational attainment by race, ethnicity, income, and region. (p. 3, emphasis in original)

Later, the document notes that “the growth of non-traditional students and students of racial and ethnic diversity and those with disabilities is altering the face of postsecondary education” and that “large disparities exist in educational attainment by race/ethnicity, income, disability, and region” (¶4, emphases added). The blueprint outlines a series of goals with recommendations, including goal three, “Increase the number of quality postsecondary credentials to meet the demands of the economy and an increasingly global society” (IBHE, 2007, p. 5).

Goal one of the blueprint, “increase educational attainment to match best-performing U.S. states and world countries” (IBHE, 2007, p. 13), includes a strategy specifically directed at “improve[d] access for students with disabilities” and a set of action steps, the first of which is reminiscent of the HEOA:

1. Improve student success in college through improved accommodation of students with disabilities through full access to the Internet and online information for students with disabilities, regardless of disability; the use of assistive technology; providing students information about careers and employment, internships, and work study, along with information about the importance of self-advocacy and how to do it.
2. Collaborate with P-20 institutions to improve transition of students with disabilities from P-12

to college, and from college to employment, including documenting employment status of students and graduates with disabilities.

3. Implement Perkins Programs of Study that specifically target individuals with disabilities (p. 13).

The IBHE Task Force (2007) documents that “only 25% of the parents of students with disabilities indicate that their child received career development training before or during postsecondary education” (p. 20), necessitating a recommendation to “improve transitions all along the educational pipeline, including from adult education to postsecondary education, from remedial classes to credit-bearing coursework, and from associate to baccalaureate degree levels” (p. 5).

Finally, the Public Agenda recommends that “a comprehensive P-20 student information system is vital for sound policymaking and accountability” (IBHE, 2007, p. 10). The IBHE’s observation that “data on students in Illinois are fragmented and inadequate to answer key policy questions regarding student demographics” (ibid.) has been the observation of the staff of the 3C Project, as well. This is in part the result of the national trend in using a compliance model of accommodation, under which students are only served if they self-identify. The model does not provide the necessary and comprehensive information to make what IBHE refers to as “sound” policy decisions. For example, the compliance model does not require a “comprehensive student information system” that tracks disabled students from secondary to postsecondary programs, particularly for those students who fall outside the purview of the Individuals with Disabilities Educational Improvement Act (IDEA). Neither does the compliance model require postsecondary institutions to compare course or program completion rates of disabled students to that of non-disabled students (e.g., a requirement in the OPE grant funding the 3C Project).

In this section I have shown how disability can be contextualized “within political and social spheres” when thinking about and engaging in policy. This contextualization is consistent with the first tenet of DSE as introduced in the beginning of this article (Connor, et al., 2009). In the next section another tenet of DSE is integrated: privileging the interests of disabled people, promoting social justice, and assuming competence.

Policy Model and Process Part II: Discourse Coalitions

Weiss (1990) has pointed to argumentation as an important factor in policy development, yet argumentation for UDL had not been fully effective prior to the OPE award funding the 3C Project. For example, a White Paper did not achieve its ultimate purpose of persuading faculty to include UDL in the strategic plan. Therefore, the 3C Project was structured around a policy process that Hajer and Wagenaar (2003) have framed as “discourse coalitions.” Other researchers also propose similar discursive processes: for example, Stone (2002) emphasizes a more dialogical process of deliberation, Fischer (2003) suggests the importance of “public enlightenment” through deliberation (p. 12), and Roer-Strier (2002) describes “raising awareness” and “building partnerships” (p. 914). To be successful in building discourse coalitions, policy activism must be persuasive to a wide range of stakeholders, particularly those who are likely supporters, by giving them what Weiss calls “talking points” and Fischer refers to as “story lines.” This increases the range of the policy discussion to include those who share or might share the policy goals, but who would be unlikely to participate in the policy discussion without such talking points.

Prior to and during the early OPE funding period at NLU, several talking points or story lines were developed. One story line points out the problems associated with compliance models as they might affect faculty and the university as discussed above. One story line has been framed this way: prior to the 3C Census, we (NLU) suspected that about 10% of our students are probably disabled, per the US Department of Education (2006), but we were not aware of who they are and could not assess their course or program completion rates, therefore we need a strategy for building institutional capacity and understanding of such issues. Another story line goes this way: the 3C Project is going to increase demand on the disabled student services office and we will not have the capacity to meet this demand unless we adopt a UDL model that serves the majority of our students. The project also created what the marketing department referred to as a “tag line”—“creating a culture of inclusion”—that encapsulates the central purpose of the project and serves as another story line or talking point. When Project staff present to stakeholder groups, they inevitably use the phrase, “everyone is responsible for creating a culture of inclusion.” Another story line ad-

resses the problems of “retrofitting” associated with differentiated instruction and compliance models and points out the benefits of UDL in avoiding the need to retrofit courses (Izzo, et al., 2008). For example, getting an accommodation letter after faculty have already finished the syllabus without regard to UDL can create anxiety and stress and minimize student access to learning opportunities. To date, anecdotal information suggests that these have helped project staff to talk differently about access and inclusion, although empirical data have not been collected to support this. In fact, Fischer (2003) notes that empirical evidence may be difficult to uncover since discourse coalition members “share a particular way of thinking about and discussing . . . issues” that cannot necessarily be “nailed down empirically” (p. 13).

According to Hajer (1993), competing story lines emerge when different discourse coalitions talk about an issue and alternatively, discourse coalitions form when actors and practices merge with a story line. Two distinct story lines are depicted (Figure 1) as permeable circles in the policy streams. Think of them as (1) a story line about the problem of the resources a UDL model may help to solve, and (2) a story line about a solution, or the benefits to faculty and students when retrofitting is avoided by using UDL. The actors and practices that conform to these story lines can be imagined as entering the broader policy stream, combining and recombining until they merge (Figure 1) and, according to Kingdon’s (2003) metaphor, remain ready for when the political climate is right and a window of opportunity opens. For example, a window might open when the political climate is such that decision-making bodies at the university have agreed on the problem and solution(s) and move to enact policy marrying problem to solution (i.e., the open window).

The above examples speak to the DSE tenet of promoting social justice. Part II of the policy activism model also is where the tenets of privileging the interests of disabled people and assuming competence can be enacted. From a disability studies perspective, discourse coalitions should solicit and include disabled people when the coalitions are formed around disability issues. In fact, DSE tenets would hold that disabled people’s interests and agendas should guide coalition efforts at defining problems, identifying solutions, and influencing politics. By assuming the competence of disabled people, a DSE framework would also assume that disabled people are the best ones to define their goals, vision, and hopes for their own postsecondary education.

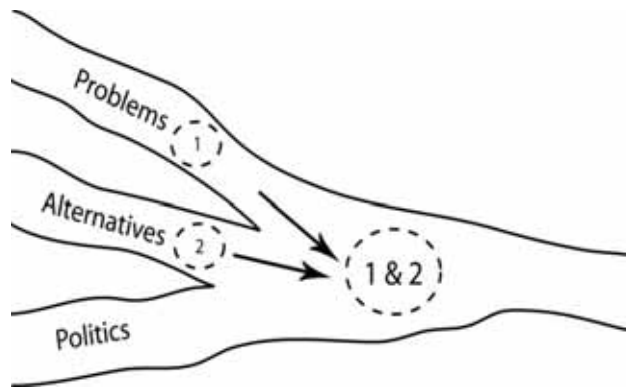


Figure 1. Model for Policy Activism

Conclusion

Two versions of the social model of disability—material and cultural—are represented in this article and in the 3C Project. Materially, the project aims to dismantle the barriers to full inclusion in postsecondary education at NLU, while the model for policy activism provides a framework that understands policy work as fluid, dynamic, political, and dependent on the deliberations and debates of discourse coalitions. Culturally, the project aims to instill the belief that it is everyone’s responsibility to create a culture of inclusion and that this entails making disability visible in a variety of ways: (1) in visual representations such as marketing materials; (2) in institutional strategies for knowing how many disabled students are attending, which programs they are in, whether they are being retained, and whether or not they view their education at NLU to be fulfilling; (3) and in understanding the types of impairments NLU students report and how the university might better meet their needs.

In my reporting of the criticisms of a compliance model of disability support services, I have implied that a disability studies perspective might minimize the compliance model’s value and uses. Indeed, while I understand it as a minimum requirement under the law and therefore necessary, I do not view it as sufficient for creating an accessible university inclusive of disabled people given the tenet of DSE that specifies “inclusive educational opportunities, and full and meaningful access to all aspects of society for people labeled with disability/disabled people” (Connor, et al., 2009, p. 448). “Full and meaningful access” cannot be achieved if only those individuals who self-identify and prove

eligibility as disabled are provided with accommodations. Consequently, a disability studies framework for postsecondary education policy would have to go “beyond compliance” (Cory, et al., 2003), using policy activism to move forward “full and meaningful access” in all ways necessary for all students.

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Professional Perspective

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In her article, Susan Gabel, discusses the 3C Project, a federally funded postsecondary education grant that seeks to provide a quality higher education to disabled students. More than her immediate discussion of the 3C Project, Dr. Gabel looks critically at the compliance model of disability support services, challenging commonly held notions of access, inclusion, and equity in an educational context. She puts forward that not until our practice is truly informed by disability studies and the social model of disability, will we see an educational culture of equity for all students. She astutely asserts that it is “everyone’s responsibility to create a culture of inclusion”...not only that of service providers or disabled students.

Dr. Gabel provides two definitions of the social model of disability that are both important to the implementation of the 3C Project and relevant to our understanding of disability. The Strong Social Model

critiques structural and institutional barriers that deny disabled people access to resources and participation in society (Shakespeare & Watson, 2001). Another conceptualization is the Social Constructionist Model that asserts that disability is defined and understood within a cultural context of symbols, rituals, and messaging (Priestly, 1998). Understanding the subtleties between these versions helps provide a more complete picture of the disability experience as related to access and oppression critical to our profession. The 3C project is informed by these models and addresses different dimensions of the educational experience, promoting systemic change that will advance our educational culture to one of inclusion. Dr. Gabel boldly asks us to look outside our immediate scope, move past our individual responsibility to facilitate accommodations, and work toward changing our culture...both that of our profession and of higher education.