How Disability Studies Scholars Interact with Subject Headings

Amelia Koford
Texas Lutheran University

Although several scholars of information organization have documented limitations in the way subject access standards represent marginalized topics, few have studied how users understand and address these limitations. This qualitative study investigates the information seeking behavior of nine scholars in the field of disability studies, focusing on how they interact with subject headings. The findings suggest that disability studies scholars often encounter and use non-preferred language when doing research and that they respond to this language in a variety of ways. The study also found that many participants prefer multidisciplinary search tools to subject-specific databases.

Introduction

The way documents are organized in libraries and databases has a profound impact on what information is retrieved and what remains unseen. Information studies writers from various theoretical perspectives, including feminism, critical race theory, and queer theory, have argued that subject access standards are politically charged artifacts with implications for social justice. Rather than neutrally reflecting the structure of reality, classification schemes and subject access vocabularies are shaped by the values of the cultures that create them. As a result, some argue, people seeking information about marginalized topics along the axes of gender, race, sexuality, and ability often experience difficulty finding materials or encounter misleading and off-putting labels.
Although several writers have documented the limitations of subject access standards in representing marginalized topics, few have studied how searchers understand, address, and circumvent these limitations. To investigate this question, a qualitative study was conducted to examine the information seeking behavior of nine disability studies scholars. Information seeking in the field of disability studies is especially complex because the field is interdisciplinary, relatively young, and concerned with people who have historically been marginalized and misrepresented in society. In semi-structured interviews, faculty members and graduate students were asked about their experiences conducting disability studies research, particularly their interactions with subject headings.

Following Olson and Schlegl, this paper uses “subject access standards” as a broad term that includes classification schemes (such as the Dewey Decimal Classification and the Library of Congress Classification) in addition to subject heading lists (such as the Library of Congress Subject Headings). In this paper, “subject headings” is used to encompass both subject headings used in library catalogs and index terms used in a variety of databases. This terminology was chosen for clarity of communication with the participants, since it was assumed that they would not conceptualize index terms as distinct from subject headings. Some of participants’ statements address particular vocabularies, while others address scholars’ perceptions of controlled vocabularies in general.

**Information behavior in critical interdisciplinary fields**

Researchers have long been interested in how people search for and interact with information. According to Wilson, librarians have conducted surveys to learn about their patrons
since at least the 1910s, with the modern era of information behavior research beginning in the late 1940s. Empirical studies of information behavior are one of several possible ways to learn about the information landscape of a particular domain.

In a 1996 article, Bates calls for more attention to the information behavior of interdisciplinary scholars, pointing out the growth of fields such as “popular culture, film studies, ethnic studies, gay and lesbian studies, and women’s studies.” Bates suggests that the concept of scatter, introduced by Mote to explain information behavior of scientists and engineers, can also be applied to interdisciplinary fields in the humanities and social sciences. Low-scatter fields are those with clear boundaries and a well-organized body of literature, while high-scatter fields span multiple subject areas and do not have a well-organized literature. Mote finds that scientists in high-scatter fields ask librarians more questions and that those questions are more time-consuming. In a 2001 study of interdisciplinary information seeking, Spanner finds that interdisciplinary scholars often experience difficulty adapting to the vocabularies and cultures of various disciplines. He also finds that they rely on references in publications and communications from colleagues more than on formal bibliographic tools.

Disability studies, as an interdisciplinary field focusing on a demographic group that is often socially and cultural marginalized, belongs to a set of academic subjects that can be called critical interdisciplinary fields. This set includes women’s and gender studies, critical race studies, indigenous studies, and GLBTQ (gay, lesbian, bisexual, transgender, queer) studies. Searchers in these fields encounter some problems common to all interdisciplinary inquiry, such as differences in vocabulary, challenges keeping up with the literature of multiple fields, and lack of library funding to add subscriptions to new journals. But unlike interdisciplinary fields such as
neuroscience and medieval studies—which have their own challenges—critical interdisciplinary studies have challenges stemming from the fact that their areas of interests are traditionally devalued in society. This devaluing affects searching in two major ways: Materials may be labeled inadequately in knowledge organization schemes, and materials may not be deemed worthy of saving in cultural heritage institutions.

Westbrook’s research on women’s studies scholars is an example of information behavior research in a critical interdisciplinary field. She finds that women’s studies scholars encountered several problems in their information seeking, including difficulty keeping up with multiple fields and frustration with the amount of time it takes to get materials. Westbrook offers suggestions for improved library support, proposing that librarians develop systems to help scholars track current research and find meaningful summaries.

This study both resembles and differs from most other studies of the information-seeking behaviors of academic scholars. Like other research on information-seeking behavior, it attempts to gain a deeper understanding of how scholars in a particular field search for information. The research questions that guide this study, however, are informed by a guiding theory about the nature of subject access standards.

Critiques of subject access standards

Critiques of subject access standards have a long tradition in the information studies literature. Authors have criticized subject heading lists and classification schemes for lack of specificity, inconsistencies, use of outdated terms, and failure to adequately represent certain concepts. The critiques most relevant to the current study are those that deal with the way
standards reflect socioeconomic power differentials, particularly the way that standards represent information about marginalized groups.

One of the foundational critiques of the representation of marginalized groups in subject access standards is Berman’s *Prejudices and Antipathies: A Tract on the LC Subject Heads Concerning People*, first published in 1971. Berman identified Library of Congress Subject Headings that, he argued, perpetuated racial, cultural, and gender stereotypes, and campaigned for alternate headings. For example, he argued against subject headings such as *Jewish question* and *Yellow peril*, which have since been changed. After the publication of *Prejudices and Antipathies*, more scholars and activists documented “bias” in subject access standards; in 2001, Olson and Schlegl identified 93 such critiques in the information studies literature.

Another foundational thinker in the field, Olson, critiques library classifications and subject vocabularies from a feminist perspective. She points out, for example, the existence of a subject heading *Gifted women* with no parallel heading for “gifted men”:

Historetically, authors writing about gifted people have focused solely on men without acknowledging this focus, while authors writing about gifted women have had to foreground the issue of gender in relation to their topic. Thus the language of LCSH perceives books about gifted men as the norm.

While Berman focuses on correcting “biased” subject headings, Olson theorizes bias as an inevitable feature of classification systems. She writes that “The problem of bias in classification can be linked to the nature of classification as a social construct. It reflects the same biases as the culture that creates it.” Furthermore, she states that a perfectly unbiased classification scheme would be impossible, since “all systems will exclude and marginalize in some way.” In order
for systems to do meaningful classificatory work, they must group together items that are similar in some ways and different in other ways. By necessity, some features of items are not represented.

Many writers in recent years have employed a critical perspective on subject access standards. In *Sorting Things Out: Classification and its Consequences*, Bowker and Star offer a historical analysis of several medical, scientific, and political classification schemes, such as the International Classification of Diseases and the system of race classification in apartheid South Africa. They write that “each standard and each category valorizes some point of view and silences another.” Furner suggests that critical race theory can be used to assess information classification schemes, and offers a critique of the Dewey Decimal Classification’s treatment of race. Drabinski uses queer theory to challenge the notion of stable classification schemes and subject categories, and calls on instruction and public service librarians to teach users to engage critically with subject headings. Feinberg argues that classification designers should make their viewpoints and goals more explicit, moving from “hidden bias to responsible bias,” and Mai writes that “classification should not strive towards being correct, but towards being trustworthy.” Narratives from activist librarian de la tierra (intentionally uncapitalized) illustrate the potential negative effects of the embedding of dominant ideologies in subject access standards. She writes that “Latina lesbians and all queers have the well-documented tradition of going to the library as part of critical soul-searching that precedes the 'coming out' process—and leaving disappointed” and that “Despite the reality that most Latin@s call ourselves Latin@, we are, by Library of Congress standards, 'Hispanic'—a term that so many of us have loathed since it entered popular use during the Reagan administration.”
Only a few researchers have offered in-depth investigations of the connection between disability and difficulty finding materials, although the connection has long been acknowledged in the literature, dating back at least to the work of Sanford Berman and Emmett Davis, a colleague of Berman’s at the Hennepin County Library. In a 1980 book, Davis and his sister Catherine Davis, a health educator, identified a number of Library of Congress headings that they considered archaic or derogatory, including *Idiocy* and *Castration of Criminals and Defectives.* Of the 93 critiques of bias in subject access standards identified by Olson and Schlegl in 2001, five mention people with disabilities. In a 2013 study of contemporary, award-winning books for youth related to disability, Kaney found that “catalog subject terms are almost exclusively diagnosis-based and provide limited insight to many important disability issues.” Most attention to disability from the information studies community focuses on topics other than subject access, especially on accessibility of electronic tools. Accessibility of physical and virtual library spaces is a vitally important topic that can be complemented by studies of subject access for materials about disability.

This project contributes to critical knowledge organization literature by providing the perspective of scholars who frequently use information systems to seek documents about a historically marginalized group. Olson states that searching for marginalized materials is qualitatively different than searching for mainstream topics:

Library users seeking material on topics outside of a traditional mainstream will meet with frustration in finding nothing, or they will find something but miss important relevant materials. Effective searching for marginalized topics will require greater ingenuity and serendipity than searching for mainstream topics.
Olson does not elaborate, however, on the nature of these creative search strategies, focusing instead on critiquing the classification schemes and controlled vocabularies themselves. Disability studies can be conceptualized as one of the “topics outside of a traditional mainstream” that Olson identifies. The field is interdisciplinary and relatively new, uses new and repurposed vocabulary, and is concerned with a group that has historically been without political and economic power. In analyzing the information seeking behavior of professional researchers using systems that purportedly marginalize their research topics, this study adds to the critical literature on subject access standards.

**Disability studies**

The participants in this study identify disability studies as one of their primary research interests. Disability studies is an interdisciplinary academic field that analyzes the meanings societies ascribe to bodily and cognitive differences. In the United States, disability studies developed as an academic field in the 1980s. Although various academic disciplines studied disability before the 1980s, disability studies scholars identified their work as constituting a new field, largely because of its emphasis on the social experience of disability and its affiliation with the disability rights movement. The disability rights movement promotes causes such as access to education, deinstitutionalization, and access to public transportation, using tactics such as legislative activism, community organizing, and nonviolent direct action.

Disability studies is a growing field. In the preface to the second edition of the *Disability Studies Reader*, published in 2006, Lennard J. Davis reflects on the changes since the publication of the first edition in 1997, writing, “It is gratifying to note that after less than a
decade…Disability studies is taught throughout the United States, the United Kingdom, and the world. Every year there are more and more disability studies degree-granting programs.***xxxv

Working in a disability studies paradigm means focusing on disability as a socially and culturally constructed category rather than as a solely medical phenomenon. Disability studies scholars do not deny the medical aspects of disability, of course; as Linton, Mello, and O'Neill write, “This shift does not signify a denial of the presence of impairments, nor a rejection of the utility of intervention and treatment. Instead, Disability Studies has been developed to disentangle impairments from the myth, ideology, and stigma that influence social interaction and social policy.”***xxxvi

This study hypothesizes that materials of interest to disability studies scholars might be poorly represented in classification systems. One of the assumptions implicit in this idea is that people with disabilities constitute a marginalized or oppressed group. This assumption is based on arguments by disability studies scholars and disability rights activists who point to the economic and political powerlessness of people with disabilities around the world. Charlton, for example, argues that “the poverty, isolation, indignity, and dependence of these 500 million people with disabilities is evidence of a major human rights catastrophe.”***xxxvii

**Data collection and analysis**

Data were collected through semi-structured interviews with nine participants. This qualitative study was designed to be exploratory, with the goal of being open to unanticipated findings and suggesting directions for future research. A purposive sampling method was used. Participants from a variety of home disciplines and academic ranks were identified and recruited,
mostly by searching online for personal and departmental profiles mentioning disability studies as a research interest. Potential participants were contacted by email, and all scholars contacted agreed to participate. Participants were required to be current faculty members or graduate students, to consider disability studies to be one of their primary research interests, and to have conducted research in the field of disability studies for at least one year.

Three of the participants were doctoral candidates, one was an assistant professor, three were associate professors, and two were full professors. The participants identified the following home departments (or disciplines, in cases without a traditional departmental structure): English (two participants), feminist studies, law, nursing, philosophy, social work, sociology and public policy, and education. When asked what gender pronouns they preferred, five said female pronouns, three said male pronouns, and one said it did not matter. Participants' ages ranged from 29 to 63, with a median age of 42. The nine participants came from six different colleges and universities, including both private and public institutions of varying sizes. This article refers to participants by number codes comprised of the letter P (for participant) and a number. Table 1 shows each participant's number code, home department or discipline, and status as a faculty member or graduate student.

Interviews were conducted between October 2011 and January 2012. Interviews ranged in approximate length from 22 to 45 minutes. Five interviews were conducted in person, three over the phone, and one through online video chat. Before the first interview, a pilot interview was conducted to identify unclear questions and generate additional questions. The interview questions focused on participants' experiences seeking information for their academic research in the field of disability studies. Questions focused on participants’ experiences searching for
published and unpublished literature rather than gathering other types of information, such as experimental data.

**Table 1: Home department and academic status of participants**

<table>
<thead>
<tr>
<th>Participant code</th>
<th>Home department or discipline</th>
<th>Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>P1</td>
<td>Nursing</td>
<td>PhD candidate</td>
</tr>
<tr>
<td>P2</td>
<td>Sociology</td>
<td>Faculty member</td>
</tr>
<tr>
<td>P3</td>
<td>English</td>
<td>Faculty member</td>
</tr>
<tr>
<td>P4</td>
<td>Philosophy</td>
<td>Faculty member</td>
</tr>
<tr>
<td>P5</td>
<td>English</td>
<td>Faculty member</td>
</tr>
<tr>
<td>P6</td>
<td>Education</td>
<td>PhD candidate</td>
</tr>
<tr>
<td>P7</td>
<td>Law</td>
<td>Faculty member</td>
</tr>
<tr>
<td>P8</td>
<td>Feminist studies</td>
<td>Faculty member</td>
</tr>
<tr>
<td>P9</td>
<td>Social work</td>
<td>PhD candidate</td>
</tr>
</tbody>
</table>

The first section of each interview focused on participants’ experiences finding information for research projects: what kind of information they needed, where they found it, the quality and relevance of the information they found, and specific databases and search terms used. In the second section of each interview, participants were asked to discuss several different representations of the same article. For example, the education scholar was asked to examine the records for one article in Education Resource Information Center (ERIC) and Education Full Text, as well as search results pages from Google and Google Scholar. Participants were asked about what they liked and disliked about each record or search results page, whether they felt that the article was adequately characterized by each information system, and what aspects of the record or search results page they noticed or used.
Table 2 lists the controlled vocabularies and standards used in the catalogs and databases discussed in interviews. Some of these vocabularies are universal, such as the Library of Congress Subject Headings, and some are special, such as the Medical Subject Headings. The list includes vocabularies used in databases that were mentioned by participants as well as vocabularies used in example records shown to participants in the second section of interviews. Some databases mentioned by participants, such as JSTOR, are not included in this list because they do not use controlled vocabularies. I attempted to accurately discern the names of vocabularies used in each database, but errors are possible since the controlled vocabularies were not always identified within the databases. More research would be needed to draw conclusions about the way any particular controlled vocabulary interacts with users’ paradigms and search practices to influence the success or failure of searches.

The interviews were audio recorded and transcribed. Data were analyzed through a selective coding process. Salient themes were identified and explored through memo writing. Participants were asked to participate in a member checking process, reading and commenting on a first draft of findings. Eight of the nine participants responded to the request for member checking, with seven saying that they felt the analysis was accurate and/or that they had nothing to change, and one suggesting small changes that were incorporated into the next draft.
<table>
<thead>
<tr>
<th>Name of controlled vocabulary (Name of catalog or database)</th>
<th>Participants who mentioned a catalog or database that uses the vocabulary</th>
<th>Participants who were shown an example record that uses the vocabulary</th>
</tr>
</thead>
<tbody>
<tr>
<td>Library of Congress Subject Headings (Library catalogs; Project Muse)</td>
<td>P2, P3, P4, P5, P6, P8</td>
<td></td>
</tr>
<tr>
<td>EBSCO Comprehensive Subject Index (Academic Search Complete)</td>
<td>P3, P5, P8</td>
<td>P4, P5, P8, P9</td>
</tr>
<tr>
<td>LexisNexis index terms (LexisNexis)</td>
<td>P2, P3, P7</td>
<td></td>
</tr>
<tr>
<td>Medical Subject Headings (PubMed; Medline)</td>
<td>P1, P7</td>
<td>P1, P7</td>
</tr>
<tr>
<td>MLA International Bibliography Thesaurus (MLA International Bibliography)</td>
<td>P3</td>
<td>P3</td>
</tr>
<tr>
<td>Law Journal Library subject headings (HeinOnline)</td>
<td>P7</td>
<td>P7</td>
</tr>
<tr>
<td>Thesaurus of ERIC Descriptors (ERIC)</td>
<td>P6</td>
<td>P6</td>
</tr>
<tr>
<td>CINAHL subject headings (CINAHL)</td>
<td>P1</td>
<td>P1</td>
</tr>
<tr>
<td>PAIS subject headings (PAIS)</td>
<td>P2</td>
<td></td>
</tr>
<tr>
<td>Philosopher’s Index Thesaurus (Philosopher’s Index)</td>
<td>P4</td>
<td></td>
</tr>
<tr>
<td>Key Number system (Westlaw)</td>
<td>P7</td>
<td></td>
</tr>
<tr>
<td>ProQuest controlled vocabulary (GenderWatch)</td>
<td>P8</td>
<td></td>
</tr>
<tr>
<td>H.W. Wilson subject headings (Education Full Text)</td>
<td></td>
<td>P2, P6</td>
</tr>
<tr>
<td>Thesaurus of Psychological Index Terms (PsycINFO)</td>
<td></td>
<td>P4, P5</td>
</tr>
<tr>
<td>Thesaurus of Sociological Indexing Terms (Sociological Abstracts)</td>
<td></td>
<td>P3, P8</td>
</tr>
<tr>
<td>ABC-CLIO subject index (America: History and Life)</td>
<td></td>
<td>P2</td>
</tr>
<tr>
<td>Thesaurus of Sociological Indexing Terms (Social Services Abstracts)</td>
<td></td>
<td>P9</td>
</tr>
</tbody>
</table>
Findings

PARTICIPANTS’ USE OF SUBJECT HEADINGS

Most participants stated that they do not regularly use subject headings to find materials in databases or library catalogs. The social work scholar and one of the English scholars said that they never use subject headings, and four participants (English, sociology, philosophy, and education) said that they use subject headings rarely. The nursing and feminist studies scholars said they use subject headings sometimes, and the legal scholar was the only one to say she uses subject headings often. These findings are consistent with other studies that suggest that directed subject searches are not typically a primary search strategy for humanities scholars.\textsuperscript{xl} This idea is supported by a statement the legal scholar made about the differences between legal research and “more generalized” disability studies research:

Legal research itself is so specific…it really is an idiosyncratic kind of a thing. I would guess the medical and scientific stuff is kind of like that too, but the more generalized disability studies things I would imagine are similar to like, critical race – more transferrable. But the legal stuff, we kind of have our own little databases and our own ways of searching for things. (P7)

Although further studies would be needed to draw firm conclusions, it seems that the perceived usefulness of subject headings is more related to scholars’ home disciplines than to their interest in disability studies. Subject headings are perceived as more useful in non-humanities, low-scatter fields such as law and nursing.
Participants gave several reasons for not using subject headings more often. In some cases, they found that subject headings did not have an adequate level of specificity. The sociology scholar stated, “I’ve never paid a lot of attention to subject headings. I just find that they’re just too broad, you get too much stuff” (P2). Similarly, the education scholar stated, “I’ve used those before, I haven’t really found them very helpful...because my stuff was so specific, and what they were giving me was not that specificity that I needed” (P6).

In understanding scholars’ dissatisfaction with subject headings, the concept of relevance criteria is helpful. Talja and Manula write that in the natural sciences, the most relevant results are generally those related to the topic the scholar is researching (topical relevance), while in cultural studies, the most relevant results are likely to be those with a particular theoretical or methodological paradigm (paradigmatic relevance). They found that literature and cultural studies scholars often saw available search terminology as unsuitable for their purposes because it did not reflect paradigmatic relevance. In the interviews with disability studies scholars, the concept of models, similar to Talja and Manula’s paradigms, was a recurring theme. A central concept in disability studies scholarship is the distinction between the medical model and the social model of disability:

The social model is distinguished from the medical or individual model. Whereas the former defines disability as a social creation—a relationship between people with impairment and a disabling society—the latter defines disability in terms of individual deficit.

Several participants mentioned the difficulty of finding materials that treat disability from a social rather than a medical perspective. The philosophy scholar said, “What I kept finding, and
I still kind of find...is that if you key in disability, whether it be through the library’s database or through Google, you still kind of get the medical model. And so I keep bouncing up against that wall” (P4). Similarly, the feminist studies scholar said, “Disability, you know, unless you search disability studies, which isn't always a word that people use, you're going to get lots of medical stuff, and that's really frustrating” (P8). She gave this example:

I think probably the hardest search that I've had to do was looking for stuff about connecting environmental movements and disability movements. Because what I was and am interested in would be stuff about environmental illness, but what I would get is just thousands of hits about, you know, epidemiology or really specific medical cases, which is not what I wanted to find. So I think particularly when you're doing a disability studies search that does get closer to medical issues, it's really hard to figure out what that line is.

The feminist studies scholar contrasted her experience searching for disability studies material with her experience searching for material in other critical interdisciplinary fields:

I think you can use a word like “feminist” or use a word like “queer,” and that’s going to be a great sorting mechanism in terms of the stance I’m looking for or the perspective I’m looking for, and that’s much harder with disability. (P8)

As P8 points out, advocates of the social model of disability have not chosen to coin a new term to describe the experience of disability as identity; instead, they have assigned new meanings to the words used by the general public and the medical establishment. As Linton puts it, “While retaining the term disability, despite its medical origins, a premise of most of the literature in disability studies is that disability is best understood as a marker of identity.”
word “disability” is used by people writing within multiple models of disability, the word cannot be used as a “sorting mechanism” to identify the theoretical perspective of the writer.

Speculating about the possibility of a “sorting mechanism,” the feminist studies scholar said, “I’m not sure what that word would be, but it would be great to have...a code word” (P8). Similarly, the philosophy scholar said, “The search terms are not fine tuned enough,” imagining a scenario “so when you key in disability it uses it in a different way than traditionally” (P4). These two scholars imagine a database or search engine that would allow them to find articles that conceptualize disability with a particular theoretical lens. A subject-specific database for disability studies might help serve this function. Another exciting possibility would be an information system that focused on paradigmatic relevance.

A few participants suggested that they avoid subject headings partly because the terms used in the headings are not their preferred terms. For example, one of the English scholars expressed a distaste for using “someone else’s words”:

For whatever reason, I’ve never been kind of high on the subject things. Maybe I just never found them that helpful, or maybe I just like using my own words rather than someone else’s words. (P3)

The feminist studies scholar made a similar comment when examining an example database record, which was for an article entitled “Integrating Disability, Transforming Feminist Theory.” In the Sociological Abstracts database, the subject headings listed were:

Handicapped

Feminist Theory

Theoretical Problems
She said:

So I'd have to search handicapped. See, I don't ever—I forget to do that. I think that's why I don't use subject headings very often. I think that I've just decided it's easier to get way more stuff than I need and have to filter through it myself than to remember to always type in these words I don't ever use. (P8)

In P8's case, the decision not to use subject headings is not just related to whether they return useful results; it is also related to her resistance to needing “to remember to always type in these words I don't ever use.” The concept of preferred language is explored further in the following section.

**ENCOUNTERING AND USING NON-PREFERRED LANGUAGE**

Many information organization researchers have identified subject headings that might be considered offensive or misleading; this study investigated participants’ responses to encountering and using those headings. During the interviews, participants discussed non-preferred language in two contexts: when describing their past search experiences and when discussing the example database records provided by the interviewer.

**Non-preferred terms in past search experiences**

One of the scholars who spoke the most about non-preferred language was P1, a graduate student in nursing. In her own writing and teaching, P1 uses people-first language. She said:

Disabled is not an appropriate term. I think that's one of the things that even APA format doesn't really appreciate, and I've been fighting every student or anybody that says
“disabled people.” It's like, “No, it's not disabled people, it's people with different abilities, or a person with disabilities.” (P1)

Advocates of people-first language contend that identifying people by their disability first, as in the phrase “disabled people,” dehumanizes them by implying that disability is the only salient aspect of their identity. They prefer the phrase “people with disabilities” because it foregrounds the individual rather than the disability. As P1 mentions, the American Psychological Association style guidelines instruct writers to use people-first language. P1 also stated that she often uses terms such as “impairments” and “functional limitations.” Using these words allows her to draw a distinction between the limitations of people's bodies and the limitations created by their environments.

Although P1 has a strong sense of the terms she prefers to use, they are not necessarily the terms she uses to search. She said:

If you're having to do a search, then until we have a paradigm shift for society, you are forced to use the language that is recognized by the, um, the librarians who don't know what maybe is, I can't say politically correct, but sensitive or aware or just, they need a paradigm shift. Yeah. So anyway...I'm forced to use those words. (P1)

In her view, finding articles related to her topic requires using words that she does not consider “sensitive or aware.” She feels “forced to use those words” in order to get useful search results. She mentioned the phrase “politically correct” but did not use it, indicating her desire to take language seriously as a marker of sensitivity and awareness. P1 also described having disagreements over language when she submitted papers for publication. When she used the phrases “chronic and disabling conditions” and “functional limitations,” the article reviewers
asked why she didn't just say “disability.” Searching is one of many settings in which P1 contends with differences in preferred terminology.

Not all disability studies scholars agree on preferred terminology for describing disability. While some, like P1, reject the term “disabled people,” others embrace it. The sociology scholar said, “The whole thing about using people first language, it becomes a very artificial way to write. I use 'disabled people' just because writing 'people with disabilities' over and over again is a bit tedious.” (P2) Preferred language can vary with time, geography, culture, and individual preference.

The sociology scholar did not object to using search terms that might be considered offensive or insensitive. He said, “I just assume that things are often based on the background of the author, or in some cases just the professional background of the person doing the categorization.” (P2) He is not troubled by using terms that might be considered insensitive; in fact, he views it as important to his research. He said: “You don’t want to leave out the words that some people might find offensive, but that if you ignore them, you might find a lot of stuff that might be very helpful to the work you’re doing.” Since he researches history and the sociology of knowledge, he is especially attuned to the cultural and historical contexts of documents and terms. He said:

I think this has been true for a lot of areas, including the non-disability work I do, is that you have to come at it from multiple directions...I think a lot of interesting questions don’t subside within a particular discipline or a particular set of terms. And particularly when one’s doing kind of critical work, you often need to find things that do not
necessarily have that kind of reflective quality, but that kind of reflect the conventional wisdom of the area you’re working in. (P2)

An anecdote from the introduction to the Disability Studies Reader illustrates the dangers of removing offensive terminology from information systems:

A bibliographer of the MLA Bibliography [said] that there was almost no way of retrieving articles or books on the cultural history of disability since proper categories did not exist. For example, an article on “crippled saints” could not be searched by computer because the word “crippled” was disallowed by MLA regulations as constituting discriminatory language. The bibliographer therefore filed the article under “saints” thus rendering it unretrievable by anyone with an interest in disability.\textsuperscript{xlvi}

In addition to being prominently placed in the well-known Disability Studies Reader, this anecdote is repeated in at least one other article,\textsuperscript{xlvii} suggesting that it has deep resonance in the disability studies community. As a parable about invisibility and erasure, it speaks to central concerns of disability studies. As a story about information systems, it illustrates the impossibility of “fixing” information systems by simply eliminating offensive terminology.

The experiences of the nursing and sociology scholars represent two distinct responses to encountering non-preferred language. One scholar had a negative reaction to being “forced to use” words she considers problematic, while another discussed the value of using search terms that “reflect the conventional wisdom of the area you’re working in.”

Although all fields develop specialized language, linguistic choices might have special salience in critical interdisciplinary fields. As Buckland writes, “Since each community has at least slightly different linguistic practices, no one index will be ideal for everyone and, perhaps,
He gives the example that “in vernacular discussion of health, the terms cancer and stroke are commonly used, but in a professional medical discourse neoplasm and cerebrovascular accident are preferred names.” The difference between the terms “mental retardation” and “intellectual disability” are more theoretically and politically charged than the differences between “stroke” and “cerebrovascular accident.” In this quotation, the sociology scholar describes the importance of language to his field:

Any specialization develops its own jargon and its own usage...if you work in a single paradigm all the time and there are some professional incentives to specialize in that way, you don’t have to be all that sensitive. But certainly within disability studies there’s a lot of concern over language, and I don’t think it’s just political correctness, I think it often reflects a kind of critical perspective on professional biases in terms of dealing with issues of impairment. So to do good work you really have to be reflective and critical. (P2)

Here, P2 suggested that disability studies is especially concerned with language partly because of its interdisciplinarity. He went on to compare disability studies to other critical interdisciplinary fields, saying:

I don’t think it’s unique to disability studies. I do think it’s probably more acute in interdisciplinary areas, but it’s also more true in areas that have a kind of commitment to social justice and social change, where there are, you know, pretty strong views about what you call things.

P2 suggested that librarians can help scholars understand the effects of seemingly small differences in language. He said:
When you’re doing research, not being sensitive to these language issues can mean that you often don’t find things from a perspective other than yours, and so I think it really can hamper the research process…That’s where good reference librarians or good research coaches, whether they’re editors or whoever, can sensitize people to how things that seem nitpicking might in fact reveal fairly profound differences in perspective. His statement suggests that negotiating the scholarly and political perspectives conveyed by differences in vocabulary is an important part of research.

Several other scholars mentioned altering their search terms to generate different results in databases or search engines. The education scholar said, “Developmental disabilities, when I was doing my search for that, I did type in intellectual, I typed in all the disabilities that fall under developmental that I could possibly think of” (P6). Altering search terms is a well-documented search strategy that can be useful in any academic field. Altering search terms might be especially necessary in the disability studies domain because there have been many historical changes in the language used to describe disability. Sinason claims that “no human group has been forced to change its name so frequently. The sick and the poor are always with us, in physical presence and in verbal terms, but not the handicapped.” A quotation from the sociology scholar illustrates this point:

There’s been a change in terminology, from mental retardation, to developmental disability, to intellectual disability. Depending on the recency of the work, I would probably use terms that are more specific to the era in which they were produced (P2).
Non-preferred terms in example subject headings

In addition to describing past research experiences, participants discussed their impressions of example database records provided by the interviewer. If we accept that any set of subject headings is an imperfect summary of a complex work, it becomes important to evaluate how well or poorly the headings perform in a given context. In this case, how well do the subject headings used in databases represent articles of interest to disability studies scholars?

As described in a previous section, the feminist studies scholar noticed the word *Handicapped* in the subject headings for Garland-Thomson’s “Integrating Disability, Transforming Feminist Theory” in the Sociological Abstracts database. The Academic Search Complete database represented the same article with the following subject headings: *Surgery, Plastic; Women’s studies;* and *Disability studies.* P8 focused on the *Surgery, Plastic* heading, saying, “Sometimes they seem random. Like, that one seems random. Plastic surgery is a very small piece of that essay.” Because of her familiarity with the article, P8 noticed that the subject headings emphasized one aspect of the article and left out others.

Another participant, one of the English scholars, also critiqued the subject headings in a sample record. Since he is interested in deaf studies, the article “Constructions of Deafness” by Harlan Lane was chosen as the example. The Academic Search Complete database represented it with seven subject headings:

*Hearing impaired children*

*Social problems*

*Influence (Psychology)*

*Applied sociology*
Human rights
Linguistic minorities
Social change

The scholar responded to the headings this way:

I don’t know that those terms are that helpful. I mean, Human rights, I guess so. Linguistic minorities, maybe. But you know, Hearing impaired, that’s not a term that Harlan Lane would use. I mean, he would say that’s part of the medical model, the hearing impaired. So you know, I might just skip over those. I don’t know that I’ve ever taken a close look at them. (P5)

The scholar noted that that Hearing impaired is “not a term that Harlan Lane would use,” and in fact, Lane critiques the term “hearing impaired” in the very article whose record was examined. He states, “it is the troubled-persons industry for deafness that invented and promoted the label in English ‘hearing-impaired’.” In a book that predates the article, Lane states, “The label has embedded within it the infirmity model that legitimates that establishment; and it exists only in opposition to hearing; in this it is like ‘non-men’ as a label for women, ‘non-white’ as a label for people of color, or ‘sexually impaired’ as a label for gays.” From this perspective, the indexer who chose the term Hearing impaired children instead of Deaf children when designing a controlled vocabulary was choosing sides in a political struggle. P5 said that he does not use “hearing impaired” as a search term and that other disability studies scholars would not be likely to use the word:

I don’t know that I’ve ever gone to Google and searched for “hearing impaired.” I mean, that’s just a term I don’t like. Even though everybody uses it, but people in disability
studies aren’t going to use that, unless they put it in quotation marks or something. Yeah, I don’t know that I’ve ever used these terms, honestly, to search for anything.

The sociology scholar also discussed example records, but did not critique them in the same way the feminist studies and English scholars did. The example article was described in the Education Full Text database with one subject heading, *Handicapped—Civil rights—History*, and in the America: History and Life database with six subject headings:

*People with disabilities—Civil rights*

*People with disabilities—Legal status, laws, etc.—United States*

*People with disabilities—Government policy*

*People with disabilities—Employment—Law & legislation*

*Disabilities—Law & legislation*

*People with disabilities—Employment—Law & legislation—United States*

While some participants responded negatively to the use of the word “handicapped” in subject headings, the sociology scholar was not bothered by it. He suggested that the differences in subject headings probably reflected the different audiences of the databases. He explained that the journal in which the article appeared is targeted to high school history teachers, and said, “The education one, maybe that reflects the fact that high school teachers are not often as current as university level” (P2). The sociology scholar’s statements, both in describing past search experiences and in discussing example records, shows that scholars do not respond to non-preferred language in a monolithic way.
OTHER SEARCH TACTICS: CHOOSING MULTIDISCIPLINARY TOOLS

Like most scholars, the participants in this study use a variety of tools and tactics to facilitate searching. In addition to discussing their use of subject headings, participants described citation chaining, searching subject-specific databases, searching the Web, consulting with colleagues, consulting with librarians, searching within particular journals, and looking for the works of particular authors. Many of these tactics have been covered extensively in the information behavior literature. Participants also described a tactic that is less well studied: choosing multidisciplinary tools over subject-specific databases.

Six of the nine participants described searching some type of multidisciplinary tool rather than specialized databases. These multidisciplinary tools included Google, Google Scholar, multidisciplinary databases like Academic Search Complete, and discovery tools. Although there are important differences between advertising-based search engines, multidisciplinary subscription databases, and discovery tools, they are grouped together here because they produce large, varied sets of results. Several participants identified a preference for sorting through long lists of results themselves.

P8, the feminist studies scholar, stated that her preferred databases are Academic Search Complete, Project Muse, and JSTOR, then said, “Women’s Studies International, and what is it called, GenderWatch? I’ve actually found those less useful than the more general ones, but I do use them.” In describing what she found more useful about the multidisciplinary databases, she said, “More hits came up. They weren’t always relevant, but more hits came up.” Similarly, P9, a social work scholar, indicated that she prefers recall to precision, saying about databases, “If I
got stuff, it wasn't wrong, it's just that it wasn't producing much.” She explained why she prefers Google Scholar to the social work databases:

I looked at the databases at [my university], but I really wasn't coming up with enough.

Like, I didn't feel like it was comprehensive...even when I selected all the databases, all the topics, I didn't get as much as I get in Google Scholar.

Several characteristics of the disability studies domain might help explain why researchers choose multidisciplinary tools. There is no database dedicated specifically to disability studies. The high-scatter nature of the field means that disability studies articles are published in many different journals. With no single database indexing them all, a global search might be the most efficient tool. Westbrook lists several reasons that interdisciplinary and area studies scholars experience problems when searching databases, including differences in terminology between databases, the fact that relevant information is distributed among many databases, and the fact that commercial companies have not invested in indexing material in newer fields.

Searching in multidisciplinary tools also facilitates serendipity. One of the English scholars searches broadly to “see if something will surprise me in some area that I wasn’t thinking of” (P3). The feminist studies scholar said:

I didn’t always know what I was looking for, so sometimes finding a broader number of hits, even though they were less relevant, I would find things that I was like ‘oh, I didn’t know I needed that, now that I see it, I need that. (P8)

The information studies literature has documented the importance of serendipity in information seeking. Talja and Manula suggest that cultural studies scholars rely more on serendipitous
findings than scientists do, since scientists are expected to be aware of all literature on a topic in a way that cultural studies scholars are not.\textsuperscript{lvii}

Several participants described being uncertain about why they were not finding material. For example, the social work scholar said, “I definitely wasn't pulling up as much as I wanted, and I don't know if it was because of the way I was searching or if it was because it wasn't there. It was probably some of both” (P9). Using a broad-based search tool may be a way to help alleviate this uncertainty. Doing a Google search might make scholars feel confident that they have found “everything” available on a topic. Seeing irrelevant results might be comforting, since it alleviates the sense described by the social work scholar that “I didn't feel like it was comprehensive” (P9). The preference for filtering through material oneself might offer a sense of control over the information. Of course, the sense that a Google or Google Scholar search produces everything is an illusion, since the Google search algorithms, like those utilized in all information systems, work from a limited collection of documents.

Choosing multidisciplinary tools is not unique to disability studies. Scholars in many fields use this search strategy. The social work scholar said that she uses Google Scholar for research that is not related to disability: “Now that I've started using it like that, it's like my go-to...I'm feeling like Google's gonna produce a lot more than the databases will” (P9). Studies have shown that Google Scholar and discovery services are increasingly important information source for researchers.\textsuperscript{lviii} Scholars of information organization should continue to investigate how Google Scholar and discovery services are changing information seeking for scholars in various disciplines, and how their use is affected by various characteristics of academic fields.
Conclusions

This study investigated how disability studies faculty and graduate students experienced the potential limitations of subject headings in representing their research topics. It aimed to empirically investigate users’ responses to the problems that critical knowledge organization scholars have identified with subject headings. The findings suggest that disability studies scholars often encounter and use non-preferred language when doing research and that they have a variety of responses to this experience. For example, one participant had a negative reaction to altering search terms, saying that she is “forced to use those words,” while another discussed the value of using search terms that “reflect the conventional wisdom of the area you’re working in.” The findings also suggest that several of the participants use non-traditional search tactics, such as ignoring subject headings and choosing global search tools over specialized databases. More research is needed to determine the ways that these tactics might correlate with particular characteristics of the disability studies domain. Flexibility and creativity are required of users, information organizers, and librarians working in this emerging domain.

The experiences of disability studies scholars can inform the work of indexers and database designers. These knowledge organizers decide on the names and arrangements of categories in the systems that people use to find information. Subject access vocabularies will never perfectly reflect reality or match the vocabularies of all potential users. As Buckland states, “linguistic expressions are necessarily culturally grounded, and, for that reason, in conflict with the need to have stable, unambiguous marks to enable library systems to perform efficiently. A static, effective subject indexing vocabulary is a contradiction in terms.” Acknowledging this contradiction, however, does not mean giving up on subject headings as useful research tools.
The dynamic nature of language necessitates dynamic systems. As disability studies grows as a field in academia, indexers should add and modify subject headings to reflect, albeit imperfectly, its perspectives.

The study results make it clear that knowledge organizers should consult with subject experts when making decisions about index terms in domains that are unfamiliar to them. The participants indicated that index terms like Disabled people and Hearing impaired communicate a particular perspective and, in some cases, can be read as offensive or insensitive. Although knowledge organizers cannot avoid using terms that reflect perspectives, their decisions should be informed by experts in the field. Of course, terminology used by experts might not be appropriate for non-experts and experts with different specializations. The specific character of experts’ and non-experts’ input into subject access standards would depend on the purpose and scope of the standard.

The concept of paradigmatic relevance surfaced several times in interviews. P4 and P8 described feeling frustrated by finding too many results reflecting the medical model rather than the social model of disability. P4 described this experience as “bouncing up against that wall” and P8 described it as “really frustrating.” P4 imagined a system "so when you key in disability it uses it in a different way than traditionally" and P8 wished for a “sorting mechanism” or a “code word.” Calling for a way to search for materials with a particular theoretical standpoint does not, of course, imply that materials with other standpoints are outside the scope of disability studies. As P2 stated, scholars often search for “things that do not necessarily have that kind of reflective quality, but that kind of reflect the conventional wisdom of the area you’re working in.” The concept of paradigmatic relevance has been raised in relation to other fields, including
critical interdisciplinary fields. For example, Olson suggests that subdivisions such as —
Feminist perspectives, —Feminist aspects, or —Feminist criticism be added to the Library of
Congress subject headings and applied to works exemplifying these perspectives rather than to
works about them.¹ If a special vocabulary or thesaurus were developed for the disability studies
domain, it would be useful to include index terms that reflect the paradigm of the work. It is not
immediately obvious what these index terms might be, since as P8 pointed out, disability studies
does not include “a word like ‘feminist’ or use a word like ‘queer’” that can “be a great sorting
mechanism in terms of the stance…or the perspective [one is] looking for.”

The results of this study also have implications for public services librarians. As
Drabinski argues, if it is impossible to design perfect subject access structures, librarians should
assume responsibility for teaching users to critically engage with those structures.¹ The 100%
response rate of this study and the liveliness of the interviews indicate that scholars are interested
in discussing the political implications of information organization with librarians. Librarians
should recognize that providing quality reference services might be more challenging and time-
consuming in emerging and high-scatter fields, where the body of literature is small, subject-
specific databases do not exist, and terminology might change rapidly. Librarians should also
keep in mind that patrons’ seemingly idiosyncratic information seeking tactics and strategies are
not necessarily signs of a lack of information literacy. Rather, these tactics and strategies might
be skilled responses to the characteristics of a particular field of study.

Several of the search tactics used by participants warrant further investigation. More
studies are needed to determine the ways that discovery services and advertising-based scholarly
search engines such as Google Scholar are changing information seeking in different domains.
Thus far, the field of disability studies has received very little attention from the information studies community. This growing field merits more attention from information studies researchers, in part because it provides an example of a young, rapidly developing field with a particular theoretical and political perspective. Scholars interested in critical perspectives on knowledge organization should conduct further empirical studies of information seeking by scholars and activists in fields such as disability studies, women's studies, and critical race studies. Groups whose members have “strong views about what you call things” (P2) provide important insight into the ethical and political dimensions of information organization, seeking, and use.


Olson and Schlegl, “Standardization, Objectivity, and User Focus.”

Hope A. Olson, “The Power to Name: Representation in Library Catalogs,” *Signs* 26, no. 3 (April 1, 2001): 646.


Ibid., 251–252.


Furner, “Dewey Deracialized.”

Drabinski, “Queering the Catalog.”


Ibid., 96.


Ibid., 159.


Ibid., 181.


Ibid., 89.


“Obsolescence in Subject Description,” 67.

Olson, “How We Construct Subjects,” 537.

Drabinski, “Queering the Catalog.”