American Folklore Studies and Disability: An Introduction

“Nothing about us without us.”

As an introduction to the special issue on folklore and disability, this essay offers a brief overview of how concerns about disability have historically been included in folklore studies in the United States. It discusses the field of disability studies and how folklore has been an important element of disability theory and writing. In making an argument for how a more serious engagement with disability studies theory and writing can enhance US folkloristics, the essay further suggests the development of a subfield of folklore devoted to disability and folklore.

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Disability in Folklore Studies: A Brief History

American folklorists have, at least since the 1980s, been concerned with relationships between folklore and disability, and that concern has been expressed in a number of ways. The overwhelming direction that this impressive body of research has taken is to focus on reflections of disability in different forms of folklore, usually to identify and explore the stigmas associated with disabilities. In some cases, this has led to examinations of pervasive ableist perspectives on the disabled, on physical appearances and intellectual or neurological differences that fall outside of the “norm.” Most early studies emphasize these forms of folklore as expressions of mainstream anxieties, for example, jokes that comment on familiar disabilities such as amputation, cancer, blindness, or sickle cell anemia, or on emerging disabilities such as those associated with HIV/AIDS (Dundes 1987a, 1987b; Fine 1987). Other studies of the 1980s in this vein include Karen Baldwin’s essay on images of Deaf people in folk narrative and Keith Cunningham’s discussion of popular ideas about disability, focusing on an amputee (Baldwin 1982; Cunningham 1989). However, this general approach to folklore and disability has remained commonplace as time has gone on. One of Susan...
Schoon Eberly’s major points in her essay on images of autistic children is that folk characters such as fairies and changelings emerged from parental and community anxieties about babies and children with birth defects and congenital disorders, such as autism (Eberly 1991). A pervasive concern in some of these studies is the notion of mainstream stigmas about disabled people. Olivia Caldeira has examined the impact of stigmas on groups of disabled young adults participating in the Special Olympics; and Amy Shuman; Shuman and Carol Bohmer; and Shuman and Diane E. Goldstein have explored the language of stigma in a number of articles (Caldeira 2015, 2016; Shuman 2015; Shuman and Bohmer 2016; Shuman and Goldstein 2016).

In other instances, folklore research that considers disability has focused on illuminating the dynamics within disabled subcultures that respond to outside stigmas. While some of these studies have only alluded to scholarship in disability-related disciplines, others have gone further in engaging some of the key theoretical tenets of disability studies, or DS (Shuman 2015; Caldeira 2015, 2016). Stephanie Hall’s study of a Deaf subculture is a particularly good example of how an ethnographic study can offer insights into the Weltanschauung of a specific community, including but not limited to their responses to outside beliefs and attitudes toward them (S. Hall 1991). Darcy Holtgrave’s work on bipolar disorder vlogs is another example of this kind of approach, as is Gili Hammer’s ethnographic study of blind women and gender identity in Israel (Holtgrave 2015; Hammer 2011). Surprisingly, though, a number of other important ethnographic studies tend to be overlooked in discussions about folklore and disability. Jean Lindquist Bergey and Zilvinas Paludnevicius’s article illuminates the perspectives of Deaf storytellers and explores the complexities of filming interviews with individuals using American Sign Language and transcribing the texts of those interviews (Bergey and Paludnevicius 2019). Douglas Baynton, Jack R. Gannon, and Bergey’s Through Deaf Eyes: A Photographic History of an American Community (2007) is thus far one of the only works devoted to photographic images of any disabled group or community and is ethnographic in its scope, offering images of Deaf people in diverse settings over a broad span of time. John L. Gwaltney’s The Thrice Shy: Cultural Accommodation to Blindness and Other Disasters in a Mexican Community (1970) is arguably the first complete ethnography on culture, folklore, and disability by a US folklorist/anthropologist. Not only was the work groundbreaking in focusing on disability, but it was radical in its time because the author is disabled and open about their disability, and they integrate their disabled perspective into descriptions of their fieldwork practices and experiences. And this was before the field of DS was established. Another important ethnographic study that should be core to discussions about folklore and disability is Nora Ellen Groce’s, Everyone Here Spoke Sign Language (1985), an ethnographic history of deafness, Deaf culture, and sign language on Martha’s Vineyard.

Besides authored texts, we should also mention editors whose collections of essays or encyclopedias have been critical in highlighting and advancing the study of folklore and disability by including entries on disability and folklore. In Trevor J. Blank and Andrea Kitta’s groundbreaking collection of essays Diagnosing Folklore: Perspectives on Disability, Health, and Trauma (2015a), authors consider a wide range of disability-related topics using diverse methodological approaches. Simon J. Bronner’s Oxford
Handbook of American Folklore and Folklife (2019) contains an essay that discusses disability along with other health-related issues (Bock 2019). And with this current special issue of the Journal of American Folklore, Editor-in-Chief Lisa Gilman, whose vision has been integral to highlighting multiple areas that have not been widely recognized in folklore study, extends her influence to include folklore and disability. As guest editor of the special issue, I add my efforts to those of others who have been consistent advocates for the importance of integrating disability concerns into folklore studies.2

In the most recent period of disability and folklore studies, authors have begun producing works that are more substantially interdisciplinary; while they reflect folkloric perspectives, they are equally grounded in DS theory. These works tend to be by authors who identify as disabled or as caretakers of disabled people; to weave together influences of DS and folklore study; and to challenge the conventional, academic discursive modes of writing. One of these is Teresa Milbrodt’s exploration of joking behaviors among wheelchair users (Milbrodt 2022). A second example is my own The Secret Life of a Black Aspie (2016), an ethnographic memoir that integrates motifs and influences of folklore, and especially Black folklore, into a poeticized narrative. Rather than relying strictly on academic prose, both works utilize creative writing as forms of analysis and theory. A third example is Phyllis M. May-Machunda’s essay that explores the complexities of being an African American mother parenting a disabled child (May-Machunda 2021).

Issues Moving Forward

In purveying published studies on folklore and disabilities, a number of issues are striking. One of these is the extent to which the term “disability” is often separated from terms such as “illness,” “chronic illness,” “sickness,” “trauma,” or “impairment,” which leads to an ambiguity about how the term “disability” is being conceptualized and defined and what is included under its rubric. Whether by design or happenstance, the way in which US folklore research has tended to consider disability is more similar to the way it might be referred to in the fields of health humanities and medical humanities than to how it is positioned in disability studies. In these allied fields, illness, disease, and sickness are often thought of as aspects of health and medicine, but not quite the same as disability. Perhaps the trend in folklore studies is in keeping with popular ideas and even with governmental and public policies in which there are some conditions that are easily identifiable and always thought of as disabilities, whereas others are only considered disabilities under certain conditions. By way of illustration, according to the World Health Organization and according to federal laws in the United States, a chronic illness is not necessarily considered a disability. In fact, many conditions that are, or can be, disabling are only recognized by federal agencies as disabilities in some cases. These include such conditions as fibromyalgia, cancer, trauma/post-traumatic stress disorder, asthma, anxiety, hypertension, HIV/AIDS, and chronic pain. The classification of these as disabilities is contingent on such factors as whether or not someone has been unable to work for a certain length of time or whether or not they are able to manage self-care.
A similarly ambiguous conceptualization of disability is reflected not only in the texts that many folklorists cite in their published work, but also in the ways in which categories of health-related conditions are labeled. For example, the often-cited text that has helped to bring disability to the forefront in folklore studies is titled *Diagnosing Folklore: Perspectives on Disability/Health/and Trauma* (Blank and Kitta 2015a), which suggests that these are three separate but related areas. Similarly, in her informative discussion that includes disability, Sheila Bock considers health, trauma, medicine, illness, neurodiversity, and disability, which suggests, again, separate but related areas (Bock 2019). The title of Bock’s essay in which she discusses the history of disability in folklore studies is “Folklore and Folklife of Body, Neurodiverse, and Ability-Centered American Identities,” and the first section of the essay is titled “Illness, Disability, Neurodiversity, and the Stigmatized Vernacular.”

A number of scholars have offered arguments that address what is, at least, a perceived justification for referring to disability apart from other illnesses or medical conditions. In their introduction to a special issue of the journal *Word and Text: A Journal of Literary Study and Linguistics*, Arlene Ionescu and Anne-Marie Callus write:

The single most important achievement of the disabled people’s movement has been gaining recognition of the fact that the difficulties encountered by disabled people in their daily lives are not so much a direct and inevitable result of biological or mental impairments but rather a consequence of barriers created by societies that take little to no account of the impairment-related needs of disabled people. (Ionescu and Callus 2018:5)

This essay, in an issue devoted to “Encounters between Disability Studies and Critical Trauma Studies,” goes on to develop the argument that in defining disability as a social construct, the social model of disability, which they consider the most pervasive, has de-emphasized the importance of impairments and other forms of illness. In other words, they argue that approaching disability as a form of social oppression and pushing back against the associations of disability with medicalization and with the idea of “defects” has led to a diminished concern with impairments as well as with the reciprocal relationships between impairment, illness, and social oppression (Ionescu and Callus 2018). In their essay, “Intersections of Disability Studies and Critical Trauma Studies: A Provocation,” Daniel R. Morrison and Monica Casper make a similar suggestion, going further to imply that the movement toward disability as identity, or as some have referred to it, disability pride, is also a factor in the tendency in DS to overemphasize the political and to underemphasize the negative aspects of being disabled, such as medicalization and debilitation (Morrison and Casper 2012).

From my vantage point, however, these assessments overstate the extent to which DS weighs the social concept of disability in relationship to the realities of impairment. To begin with, the social model has not been the only influential model in DS, and it has often been in conversation with other models, such as the phenomenological model and the model of complex embodiment. The phenomenological model emphasizes the lived, embodied experience and the integration of this experience with social forces. Similarly, the model of complex embodiment considers elements of embodiment,
including medical interventions, pain, quality of life, assistive technology, environmental factors, and how all of these in conjunction with ableist social forces impact disabled people. Twentieth-century and twenty-first-century DS theorists who have most influenced the field have been acutely aware that relying solely on the social model leads to an unbalanced and undesirable perspective on disability. Tobin Siebers devotes considerable time to this issue in his discussion of disability studies and identity politics (Siebers 2008:70–95), as do other DS scholars. He notes that the social model as an extreme response to the medical model, which focused exclusively on impairment, would lead to a complete oversight of the body and issues related to it, such as pain, illness, and medical interventions. I would imagine that those most familiar with some of the canonical work in DS by authors such as Rosemarie Garland-Thomson, Lennard J. Davis, and Siebers would have gathered that the experiences of embodied disability, rather than being overlooked, are at the heart of their theory and discussions, as is an expansive view of what the term “disability” can encompass.

Besides avoiding unnecessary confusion, there is also an additional reason for refraining from a list of related terms when writing about disability. The term “disability” has been reimagined and re-defined through decades of academic, theoretical, activist, political, and advocacy work in ways that the associated terms have not. As such, it is difficult to use some of these other terms without reinforcing the negative stereotypes and stigmas that those of us invested in issues of health would like to dismantle and eradicate. For example, all too often, articles such as those on “sick” humor are testimonies to how the resonances of the term “sick” extend well beyond simply designating a state of illness to signifying something as “disgusting” or perverse. At the same time that such articles denounce the stigmatization of people with a range of disabilities, they can also serve as spectacles that invite the reader to share in the “sick” laughter that the jokes might invoke. Hence, rather than debating when an illness, sickness, or trauma is a disability, I am using the term “disability” in this essay to apply to all of the conditions suggested by related labels and at the same time to designate a certain kind of social and political oppression.

A second observation about works in US folklore and disability and health-related research is that they are often absent of any substantial engagement with theories from fields such as DS, health humanities, medical humanities, or trauma studies, as if these fields and the theoretical currents within them do not exist. Instead, authors often reference scholars such as Erving Goffman, whose work was certainly groundbreaking and remains relevant to issues of performance and disability (Goffman 1956, 1963). Nonetheless, works such as his are too dated to have benefitted from scholarship, theories, or attitudinal shifts that have occurred over the last five or so decades. While the oversight of more current work in disability-related fields may be understandable when considering works from the 1960s–1980s, beyond these decades, it is puzzling. One would certainly expect work from DS and related fields to be consistently, rather than rarely, engaged and referenced by folklorists concerned with disability in the decades following the 1980s. Unfortunately, articles in which an engagement with DS is absent have led in some cases to research and arguments that are unwittingly “out of step” or even counter to some of the fundamental interests and social positioning of many disabled people. Furthermore, avoiding serious
engagement with prevailing theories that position disability as not simply an issue of embodiment but also as one of social and political imagination, discourse, and power makes it difficult, if not impossible at times, to fully recognize, validate, and advocate for disabled people. For example, in folklore studies involving disabilities, a number of the most fundamental terms from disability studies and allied fields, such as “ableist” and “ableism,” are rarely used.

A third observation is that there are few works considered under the umbrella of US folklore studies in which the author self-identifies as disabled, suggesting that within the field, the stigmas about disability have played an important role in the kind of folklore and disability work that might be acceptable and in how people with disabilities, including professional folklorists, are perceived.

And finally, a fourth observation also involves definition and terminology: How do we define US folklore studies? Many of the scholars who have made important contributions to folkloristics (and this applies to the area of folklore and disability as much as to any other subject area) are from other disciplines and have not necessarily identified themselves as “folklorists.” Then what criteria do we apply to determine if particular scholarship or other kinds of work will be considered folkloristics? To be clear, I am posing these questions not as ones to be answered here, but as ones whose considerations might lead us to think more broadly and productively about the area of folklore and disability studies.

Disability Studies: A Brief History

As a field, disability studies is rooted in a global movement of activism and protest insisting on human dignity and equal rights for disabled people. It is grounded in a keen awareness of the long history of egregious and systematic stigmatization that disabled people have been subject to and in a determination to change the laws, public policies, institutional practices, and public attitudes that continue to make these abuses possible. In other words, disability studies projects are inherently political, in much the same way that Black studies, or women’s and gender studies are. In fact, it can be unproductive to compare disability studies and folklore studies in the same ways that we might compare folklore studies programs and English departments. Disability studies is in many ways more comparable to theoretical perspectives or discourses such as critical race theory than it is to many traditional academic fields or departments. One can be a historian, engineer, sociologist, medical doctor, economist, scientist, or literary scholar and position oneself and one’s work in DS. Hence, this complicates the question that is sometimes raised by those in traditional fields and that folklorists reading this special issue might be inclined to ask: “How would DS benefit from the perspectives, theories, or methodologies central to our field?” The complication does not diminish the importance of asking or of developing reasonable responses at times; however, it is important to note that the question would best be answered if it focused on some particular issue that affects specific disabled people in situational contexts rather than addressing it on the macro level of theory. In some instances, the answer might be that folklore studies may not be very useful at all, for example, in the diagnosis process for someone with intellectual or physical...
disabilities. Undoubtedly, though, there is common ground between the two fields that could, in other instances, make folklore studies invaluable to DS. Not only has folklore studies consistently advocated for what has essentially been marginalized individuals and populations, but its ethnographic research methods and focus on the particulars of interpersonal, intragroup, and intergroup communication can offer insights and perspectives that could expand disability-related research in significant ways. Hence, in certain contexts, folklore studies could be of tremendous help to DS and in projects involving disabilities, for example, in evaluating the social behaviors of autistic children or in looking at the impact of medical or public policies on disabled people within a given community.

The disability movement of the 1960s, whose strategies were inspired to a great extent by the Civil Rights Movement, was undoubtedly a major influence on the passing of legislation that recognized the institutional biases against disabled people and sought to address them. The movement is also largely responsible for the genre of disability literature and for the emergent scholarship and theoretical discourse that led to the development of DS as a field and its growing presence within colleges and universities. It is important to note, though, that the movement occurred over time, marked by many milestones, such as the formation of the League of the Physically Handicapped in the 1930s; the We Are Not Alone organization in the 1940s, founded by a group of psychiatric patients; the beginning of the National Barrier-Free movement in 1950; and the Independent Living movement in the 1960s.

One of the core concepts in DS is that of “ability,” which aligns with another concept, “ableism,” and which is comparable to other institutionalized systems of ideology and oppression, such as racism or sexism. Undoubtedly, some engagement with the long-standing ideology of “ability” is necessary if one is to seriously focus on disability, as it is generally recognized as one of the most powerful sociopolitical ideologies affecting disabled people. As one author writes, “the ideology of ability is at its simplest the preference for able-bodiedness. At its most radical, it defines the baseline for which humanness is determined, setting the measure of body and mind that gives or denies human status to individual persons” (Siebers 2008:8). In erasing a good share of the population from the category of “human,” the ideology of ability betrays a persistently limited and ultimately malevolent imagination. This ideology not only determines the will of political institutions but permeates the culture and “affects all of our judgments, definitions, and values about human beings, but because it is discriminatory and exclusionary, it creates social locations outside of and critical of its purview, most notably in this case, the perspective of disability” (Siebers 2008:8). As this critique suggests, an entire foundational worldview must be unpacked and upended before the realities of disability can be fully appreciated, for, as Siebers notes, there is simply no place for fully validating the lived experiences of disabled people within the ideology of ability.

It is difficult to overstate the impact of the ideology of ability or its role in furthering the politics of power and maintenance of social caste systems of ability. Ability invokes strategies of shaming and guilt to perpetuate practices of secrecy and to enforce exclusionary customs and traditions that have been maintained not only by institutions, but often by communities and families of those who are disabled. And ability
sanctions rituals of ridicule, ostracism, and physical and symbolic violence against disabled people.\(^8\) One encounters these influences at every turn. They are prominent in the architectural designs of most physical spaces that simply deny entry, or once accessed, pose formidable barriers to the participation of many disabled people. They are prominent in all levels and registers of language, from the most formal to the most informal.\(^9\) And they are present in social expectations for modes of communication, social interactions, and appearance, whether in casual or professional contexts.

Another fundamental tenet of DS emphasizes the necessity for being aware of the long history of ableism, as it has existed across time and among many cultures throughout the world. It is not uncommon for authors to allude to this history in their writing, in scholarly or creative modes. To recount this history not only provides an important context for contemporary experiences and challenges that disabled people face, but can also be a way in which authors affirm their own identification with communities of other disabled people, not only in the present time, but throughout history. Most often, rather than providing a detailed account, authors allude to a few representative examples, such as in the United States, the eugenics movement,\(^10\) and the “ugly laws” that made it illegal for disabled people deemed visually offensive to even be in public.\(^11\)

As DS is, by its nature, ever evolving and interdisciplinary, a number of interdisciplinary subfields have emerged in the last decade or so. One of these interconnects disability studies and Black studies and is sometimes referred to as Black disability studies (Hinton 2021). The subfield grew out of responses to the inadvertent Whiteness of DS and, in particular, to the failure within the field to center concerns of race and to imagine how such concerns might trouble some of the theories and unspoken assumptions underlying them. This work began with Christopher M. Bell’s scathing essay in which he states: “On that score, I would like to concede the failure of Disability Studies to engage issues of race and ethnicity in a substantive capacity, thereby entrenching whiteness as its constitutive underpinning” (2006:275). Nor was Bell’s the lone voice expressing such disillusionment. It was several years later, when his edited collection of essays *Blackness and Disability: Critical Examinations and Cultural Interventions* (2011) was published that a number of other scholars began writing in this area, and the subfield of Black disability studies emerged. One of the important understandings of this subfield is that Black people’s writing about disability preceded the field of DS, for example, in works such as Audre Lorde’s *The Cancer Journals* ([1980] 2020) and even in much earlier works, such as Harriet Jacobs’ *Incidents in the Life of a Slave Girl* (1861). Within Black disability studies, there has also been an argument for a Black feminist disability framework, comparable to the creation of feminist disability studies, pioneered by Garland-Thomson (Bailey and Mobley 2019). Thus, a recent interdisciplinary focus includes the areas of Black feminism, Black studies, and disability studies. While this is only one of a number of interdisciplinary directions in which disability studies has grown, others have also emerged, for example, architecture and disability (Gissen 2022), music and disability (Howe et al. 2015), disability and literature (Barker and Murray 2018; A. Hall 2015; Mitchell and Snyder 2000a; Quayson 2007), disability and queer studies (McCruer 2006; Kafer 2013), and disability and postcolonial studies (Puar 2017; Falola and Hamel 2021).
Folklore and Disability: Toward Interconnections and Interdisciplinary Perspectives

As it turns out, there is an abundance of resources focusing on disability and folklore, although much of it has been by authors outside of US folklore studies. This is, in part, my rationale for posing the earlier question about what materials should be considered under the folklore studies rubric. Disability studies scholars and authors from a variety of disciplines have created a substantial body of literature on folklore and disability. An obvious, shared focus of both disability studies and folklore studies is a profound commitment to better understanding the nuances, implications, and diverse facets of culture and social communication. Like folklorists, DS scholars have proven themselves to be critical purveyors of culture, inclusive of institutions, customs, traditions, and forms of artistic expression (Bell 2011; Snyder and Mitchell 2006; Charlton 1998; Clare 2017; Davis 2002; Ellis 2015; Garland-Thomson 1997, 2000; Iwakuma 2011; Lockman 2015; Stone-MacDonald 2012; Stone-MacDonald and Butera 2012a, 2012b; Stamm 2004). A difference between the two fields has to do with the greater focus on disability by DS scholars versus the more wide-ranging focus within folkloristics.

The primary purposes for considering folklore within DS work has been (1) to better illuminate the experiences of disabled people, relative to the dominant, ableist culture, (2) to better understand, critique, and dismantle behaviors and ways of thinking that limit or oppress disabled people, (3) to explore, appreciate, and even to celebrate and affirm folklore and perspectives within disabled communities and among disabled people, and (4) to better assist in social and political work that positively affects disabled people. As such, folklore is important for its potential of shedding light on social structures, community and interpersonal dynamics, and relationships between disabled people and institutions in order to influence social attitudes, cultural practices, public policies, and laws. Folklore is just as important for its potential to validate and affirm disabled experiences and cultures and to offer strategies for maintaining and improving one's physical and mental health and care. This perspective brings with it a different hermeneutical lens through which traditional ethnographic practices, cultures, and elements of culture are viewed and often requires that different kinds of inquiries be made. To what extent is some of the lore that we might be inclined to celebrate and conserve rooted in ableist perspectives? Who, and where, are the disabled in any particular group? How are they treated? What are their experiences, and how might their perspectives invite different insights and critical analyses about the group in question and their folklore? Where are the disabled in the tales, jokes, rituals, proverbs, or festivals of a particular group? How are they positioned in articles, films, books, and other folkloristic productions? To what extent do they and their perspectives and experiences shape the scholarly theories, analyses, and reports rendered by folklorists? To what extent do they and their experiences disrupt and complicate the conventional ways of imagining groups, social discourse, aesthetics, and so on? These are all questions worth considering when contemplating the potential for interdisciplinary works in folkloristics and disability studies.
Disability studies has not only discussed folklore as one of the key cultural forms that reflect popular ableist attitudes but has also focused on folklore-related forms that function in a variety of ways within disabled communities. Exemplifying the former, proverbs have often been considered in the context of social and political power, the power of custom and tradition, and the power of institutions grounded in the ideology of ability, and how these manifestations of power impact the disabled. It is common for DS scholars to discuss proverbs and folk speech that reflect ableist attitudes and the institutional power behind them. Such discussions explore proverbial speech in a myriad of contexts, such as popular music and in naming practices. In discussions of proverbs and disability, scholars focusing on African cultures have been particularly invested in interrogating the impact of cultural traditions and attitudes on the disabled (Ogechi and Ruto 2002; wa-Mungai 2009; Devlieger 1999; Moasun and Mfoano-M’Carthy 2020).

Stories and storytelling are also prominent topics in DS. Furthermore, storytelling is a recurrent discursive form of writing in the field, so much so that one could reasonably assert that no other form recognized by folklorists is as important. Storytelling is also a common mode of expression that plays critical roles within disability communities. While a few studies offer disability-centered analyses of folktales (Schmiesing 2014), others have focused on structural elements in narratives that disabled people tell about their experiences in genres such as legends and beliefs and in conversation or life writings (Kitta 2019; Couser 2009; Frank 2013; Milbrodt 2018). There is an abundance of life writings that can be considered auto-ethnographic and that offer detailed descriptions of or explore folkloric materials (Clare 2015; Prahlad 2016, 2024; Wong 2020; Kasnitz 2019). In fact, auto-ethnographic writings are so common that some have objected to the assumptions that this will be a “go-to” form of writing for those focusing on disability. In addition to writings that may be more personal or creative, there are also a number of exceptional ethnographic studies by disabled and non-disabled folklorists and anthropologists that investigate disabled communities in a more conventional academic mode, integrating storytelling as an integral element of cultural dynamics. These include Karen Nakamura’s (2013) classic ethnography of an institutionalized community of people with schizophrenia in Japan. And finally, when discussing storytelling, we must consider studies of disability in literature, as all literary genres involve some kind of storytelling and folklore, and literature is a well-established area within folkloristics (Barker and Murray 2018; Hall 2015; Mintz 2007, 2013; Bell 2011). In fact, some of the most provocative disability theory has emerged from studies focusing on literature and points to interesting avenues for further research in folklore; for example, Ato Quayson’s theory of “aesthetic nervousness” (2007) and David T. Mitchell and Sharon L. Snyder’s theory of “narrative prosthesis” (2000a).

The area of disability and humor has also generated quite a bit of discussion and has focused on humor and jokes in a variety of contexts and communities, including stand-up comedy, cartoons, counseling sessions, social media forums and communities, interpersonal communication, and film and television (Berger 2013; Milbrodt 2022; Bingham and Green 2016; Abujbarah 2019; Chadwick and Platt 2018; Haller and Becker 2014). Although some of these offer analyses of ableist humor, others
are concerned with humor among people with various kinds of disabilities. Teresa Milbrodt, for example, explores how people with physical disabilities joke about their disabilities in ways that deconstruct ableist attitudes in dominant culture and, in so doing, re-define themselves in empowering ways (Milbrodt 2022). Like other studies, this one is grounded in previous theory on humor and on the psychology and social functions of joking behavior.

Disability and ritual is another area that intersects with folklore and often involves genres of religion, folk healing, and medicine (Murphy et al. 1988; Longmore 1997; Pearson 2011; Groce and McGeown 2013). As with studies in other genres, some of these are grounded in theory that would be familiar to folklorists, although their subject matter and points of emphasis are related specifically to disability and issues of concern for disabled people. Robert F. Murphy, Jessica Scheer, Yolanda Murphy, and Richard Mack (Murphy et al. 1988) discuss the concept of liminality and how it can help in better understanding the role of ritual in the lives of people with acquired disabilities. They write that “the disabled are viewed as being in a ‘liminal’ state, as in the liminal phases of rites of passages. They are persons having an undefined status” (Murphy et al. 1988:235). Nora Ellen Groce and Julia McGeown explore the cultural link between witchcraft and disabilities that in part account for a rise in incidences of ritual ceremonies targeting disabled people that can lead to the mutilations and death of both adults and children (Groce and McGeown 2013). Such works remove studies of ritual from the realm of theory, repositioning them instead in the realm of social practices that affect disabled people.

Studies of visual culture within disability studies often intersect with materials of interest to folklorists. Such studies focus on a wide range of media, including traditional and fine art, commercial entertainment, advertisements, and television and film (Nelson 1994; Garland-Thomson 2000, 2009; Millett-Gallant and Howie 2017; Mitchell and Snyder 2000b; Crutchfield and Epstein 2000; Snyder and Mitchell 2010; Millett-Gallant 2010; Stamm 2004; Prahlad 2022). In their focus on visual language, some of these studies offer exciting opportunities for folklorists to expand some of their conventional approaches. For example, while folklorists have historically been interested in performance and audience, they have seldom explored the nature of seeing, the gaze, or particular modes of seeing, such as staring, and the interactions between looking and behaviors or performances of those who are the objects or subjects of the gaze. Perhaps because the status of disabled people has so often been defined by the gazes of others, there is ample work in DS that explores such visual languages as staring (Garland-Thomson 2009; Hevey 1992).

Interestingly, folklorists have not generally been interested in a particularly rich source of not only visual culture, but folklore in general—circuses. Yet “freak” shows and circuses are recurrent points of reference in disability studies, which is easily understandable, as circuses provide glimpses into the mainstream treatment and ways of imagining those with disabilities. Further resources that would be of interest to folklorists can be found in studies of and productions in photography, cinema, and television (Norden 1994; Mitchell and Snyder 2000b; Snyder and Mitchell 2006; Markotić 2016). Disability studies scholars have offered a number of schema mapping the motifs and common character types found in forms of visual culture. Some
of these would surely interest those studying folk narrative and would undoubtedly trouble some of the common folkloristic interpretive approaches to storytelling in productive ways. For example, viewing Stith Thompson’s tale types and motifs (1932) with Martin F. Norden’s schema for disabled characters (1994) invites exciting possibilities for analysis.\textsuperscript{15}

There are intersections between folklore and other areas that disability studies scholars have focused on, for example, speech and sociolinguistics, music, and history. A number of studies offer fascinating possibilities for ways to approach folk music, including the blues (Rowden 2009; Lerner and Straus 2006; Straus 2011; Bailey 2011). In fact, emerging DS work addressing African Americans and race transforms conversations about many facets of colonialism and Black culture, folklore, and histories that would lead to different kinds of analyses of such forms as jazz, dance, tales, storytelling, healing, and folk medicine (Leary 2005; Boster 2013; Jarman 2011; Jackson 2011; Drazen 2011). Another particularly exciting area of research draws upon sociolinguistics of sign language and, within this area, studies of Black American sign language (Lucas 2001; Lucas et al. 2016; McCaskill et al. 2011; Hill 2017). And finally, the focus on disability and dance in disability studies is an emergent strength within the field and has already offered theoretical paths that accent and expand upon previous approaches (Whatley et al. 2018; Sandahl and Auslander 2005). In particular, studies and creative work in the area of dance and disability highlight nuances of embodiment, giving new meanings to “intertextuality” in the realms of writing, interdisciplinary scholarship, readings, and live performances: for example, Petra Kuppers’s integration of dance, theater, somatics, and poetry, as well as her willingness to publish books in an open access format (Kuppers 2014, 2017, 2022). The international program, DanceAbility, has also generated a bibliography of written sources as well as solidified performance spaces for disabled people that re-define the world of dance and ways of thinking about disability, movement, and art (Herman and Chatfield 2010).\textsuperscript{16}

\textbf{Reasons for Interdisciplinary Study:}
\textit{The Disability and Folklore Studies Special Issue}

There are substantial reasons for encouraging further study in the areas of folklore and disability; in fact, I would encourage the development of a subfield of folkloristics that focuses on this area. Numerous folklorists have been, for some time, committed to studying and writing about folklore and disability in ways that offer important insights, effectively laying a foundation for an interdisciplinary focus.\textsuperscript{17} To begin with, there are very practical considerations for developing this subfield, beginning with the realities of contemporary societies. According to the Centers for Disease Control and Prevention, 27 percent of adults in the United States are disabled and, according to the World Health Organization, over 16 percent of the global population is disabled.\textsuperscript{18} While such statistics can never be completely accurate and are undoubtedly conservative,\textsuperscript{19} they are informative, just as are statistics that indicate that a large percentage of disabled people live below the poverty line. Such political issues as the global rise of White nationalism and instabilities of democratic governments are invariably leading...
to an increase in not only mental but physical disabilities. The same can be said of the all-too-frequent occurrences of mass shootings and police-sanctioned tortures and executions, the escalation of wars, and epidemic of homelessness. Climate change with resulting hardships such as famine, food instability, migration, and disease will dramatically increase the numbers of people with diverse forms of disabilities. As a case in point, asylum seekers worldwide have often incurred physical and mental disabilities resulting from crises such as wars or lack of health care. In studies that have been conducted and that look at a variety of countries in different parts of the world, the prevalence of PTSD (post-traumatic stress disorder), depression, and anxiety disorders among refugees is extreme, in some cases affecting entire populations (Fegert et al. 2018; Blackmore et al. 2020; Hameed, Sadiq, and Din 2018). The pronounced impact of plastic and other forms of pollution as an inescapable element in the global food chain is predictably going to result in a rise in many forms of illness and disability, not to mention the overwhelming percentage of aging populations in many countries, including the United States. According to the US Census Bureau, by 2030, people 65 and older will outnumber children (Schneider 2023). Given the inevitability that most of us in our lifetimes will be touched by disability in one form or another, it only makes sense that we would want to extend our professional interests to include disability-related issues. Furthermore, disability crosses all demographic and geographical boundaries; in fact, it reaches across all social, political, gender, racial, ethnic, or other kinds of traditionally accepted groupings and divisions.

Given the inevitable increase in numbers of disabled people, along with more widespread attention to disability concerns, it is likely that disability-related jobs will also increase, affecting many professionals in many disciplines and creating career opportunities that may not have existed 20 years ago. Although the long-standing assumption that work in the humanities does not have any direct social or political impact has been challenged and disproven, particularly in folklore studies, it sometimes resurfaces in disability-related work, for example, in such suggestions as “our work rarely changes the conditions of stigma that produce dehumanizing difference, even if we make it more audible or more visible” (Shuman, quoted in Blank and Kitta 2015b:9). I believe, however, that such expressions are more a reflection of a frustration with how slowly attitudes and policies may change than a sincere belief that our efforts are futile. In fact, sentiments like these are indications of the profound care that folklorists have for those we work with and on whose behalf we are often advocates and activists. Our work as folklorists often does have a tremendous impact on individuals and communities that we work with, and this is more and more the case as folklorists become more invested in causes of social justice. In the realms of disability, health, and medicine, many health care practitioners in diverse fields read books and articles by authors in the humanities and are influenced by them, including writings in disability studies. This has been one of the missions of the fields of health humanities and medical humanities, and, to some extent, the efforts to have medical students and practitioners engage with disciplines in the humanities has been increasingly successful. This is evident, for example, in the kinds of papers delivered and discussions at conferences such as the annual meetings of the Health Humanities Consortium. Furthermore, many people whose lives are affected by disabilities are
especially interested in writings about disabilities and particularly those writings that relate directly to the conditions that affect them and the people they are close to.

Besides the possible career opportunities that a background in folklore and disability studies might engender, coupled with the potential for influencing the medical and social care and/or the mental state of people affected by disabilities, a more concentrated concern with disability issues could affect the field of folklore in positive ways. As the essays in this special issue highlight, a serious engagement with disability and disability studies can help folklorists to reimagine some of the fundamental elements of our field: for example, people, communication, community, performance, aesthetics, tradition, groups, and genre. It can lead us to reimagine them in ways that expand our current theoretical, methodological, disciplinary, and hermeneutical reach. For example, disability disrupts conventional notions of groups and invites us to consider that folk groups can rest upon shared experiences of being disabled as well as and instead of on the more frequently recognized identities. But even within the kinds of groups that folklorists are accustomed to discussing, there are often disabled groups, and within these, there are smaller groups of people with different types of disabilities. This recognition of inherent intersectionality certainly complicates things. And to trouble them even further, many disability communities exist only in virtual spaces. It then behooves us, if we are serious about integrating disability and folklore studies, to allow these realities to reshape some of our ways of imagining folklore studies, along with its theories and methodologies, and importantly, its missions.

An interdisciplinary approach could lead us to interrogate some of the most basic ableist assumptions historically underlying much of what we do, in theory and in praxis. In the scholarly realm, it has implications for the way in which folklorists think about ethnography and ethnographic practices and about the essential missions of folkloristics. But it also could shift our thinking about the praxis in our day-to-day lives, in our roles as scholars, educators, activists, and advocates. For example, what is our disciplinary etiquette, and what are our in-group assumptions about fundamental elements of social interaction? How accessible are American Folklore Society conferences, publications, and programs for those with diverse kinds of disabilities? To what extent do academic folklore programs consider the disabilities of their students in their pedagogical practices as well as in the models offered for how to do ethnographic research, how to create analytical and creative texts, and, in the options available to disabled students, for whom these models are unreasonable or don’t work? To what extent do folklore programs require educational competencies that pertain to disabilities or prepare their students to work with disabled people? As Siebers notes, “one of the basic claims of disability studies is that the presence of disabled people in any discussion changes not only the culture but also the nature of the arguments used in the discussion” (Siebers 2008:4)

The Special Issue

The essays in this issue invite us to imagine the world through the lens of disabled people and those who care for or who work closely with them, and those who are allies of people with disabilities. But further, they insist on this expanded vision that
I have outlined. The authors invite readers to imagine the immeasurable difference it would make if we approached all of our materials from a disability-centered rather than an ability-centered ideology. If, for example, when we consider communication, we also imagined Braille, American Sign Language (ASL) or other visual languages, subtle nods by those who cannot move their heads because of spinal disabilities, ticks, stutters, autistic repetitions, the smiles of those with dementia, stares, silences, or people’s conversations with animals and plants. If, when we write about “people” or “communities,” we acknowledge the abled and disabled experiences and the perspectives of both those with whom we work and ourselves, we might further understand the impact of ableist social and political forces that shape our points of view and our creative and scholarly work. These essays point to a conclusion that folklore studies in the United States has been inching its way toward over the past few decades. The knowledge systems, reflections, philosophies, and perspectives of not only disabled people, but of any folk or folk groups are a form of theory and should be regarded as such. Rather than reducing them to objects of study positioned within theories developed by others, or as Alan Dundes refers to it, “grand theory,” we should meet them on their own terms, which include accepting diverse forms of expression and communicative modes as intellectually equal to traditional academic discourse (Dundes 2004; Noyes 2008, 2016). Indeed, this acceptance is one of the most important contributions that folklore studies can offer, not only to a subfield such as folklore and disability studies, but in general.

In the essays that follow, Allison Stanich (2024) argues that the neurotypical world is unable to recognize its own social and communicative customs as a stage on which neurodivergent people have to mask or “perform” neurotypicality in order to survive. Through her participation in a number of online communities, she highlights a recent movement among neurodivergent people to refuse to mask and instead to insist on being themselves in the mainstream world. Amy Shuman and Olivia Caldeira (2024) discuss the history and importance of plain language, focusing on the elements of competence and consent and how such issues are especially relevant to folklore studies. Andrea Kitta (2024) examines the illnesses, COVID-19 and Long COVID, and the disjunctures between the experiences of those with these illnesses and public and medical ideas about them. In the process of describing her own experiences with Long COVID, she interrogates a number of ideological pillars of folkloristics, for example, whether telling stories is necessarily in one’s best interest, the role of unacknowledged beliefs held by folklorists, and the impact these have on our work. Nora Ellen Groce (2024) suggests the immense potential for folklorists to play significant roles in the work of local and global organizations charged with the health issues of people in regions in which they work. The knowledge of folklore could offer important insights that would help not only healthcare workers but populations of people within a particular culture to address problems that impact their health. As an artist, engaged with “folk” and fine art and artists, Ann Millett-Gallant (2024) discusses one of her paintings, “Self-Portrait: Waking Up with/to Cat Companions.” Although not a folklorist, she notes some of the folkloric associations with cats and how her painting draws upon these to suggest empowering aspects of her identity. Gwendolyn Paradise (2024) demonstrates a more complex relationship between disability, indigeneity, and the
ongoing impact of colonialism than has previously been noted. Through interweaving colonial stories about the Cherokee and her mother’s stories, along with her mother’s Alzheimer’s and her own worsening disability, she offers a model for a different kind of ethnography. In detailing some of her experiences as a parent and caregiver of an autistic child, Phyllis M. May-Machunda (2024) calls for folklore studies to research the narratives of children with disabilities and their caregivers. She urges folklorists to view the experiences of children with disabilities as partially shared collective identities for their families and caregivers and to embrace intersectional analyses of the specific knowledges and disability experiences of BIPOC (Black, Indigenous, [and] people of color) children and their caregivers. Traci Cox (2024) provides a personal account of the damage that institutional and familial ableism can cause for people with attention-deficit/hyperactivity disorder (ADHD), while suggesting the close connection between folklore studies and disability studies and the potential for research in folk medicine and disability. Teresa Milbrodt (2024) interweaves an ethnographic account of how her vision impairment impacts her day-to-day life, including teaching and conducting folklore research. Her essay disturbs long-standing ideals and images of university professors and students and opens multiple avenues of discussion, relative to institutional and pedagogical assumptions about who we are, what we do, and how we do it.

It is my hope that this issue will make a compelling case not only for a greater inclusion of disability studies in folkloristics, but for the evolution of an interdisciplinary subfield of folklore and disability, and will offer examples of some directions in which such intersections might unfold. Ultimately, disabled people and those close to them should be at the forefront of such a development, for as the long-standing disability proverb suggests, “nothing about us without us,” and as the Jamaican proverb attests, “who feels it knows it.” It is my sincere hope that those folklorists with an investment in the well-being of disabled people can (1) work toward establishing an organizational presence and greater awareness of DS within the folklore field, (2) begin to build a corpus of publications about folklore and disability, and (3) highlight disability in public arenas such as exhibitions and performances. Moreover, I look forward to seeing folklore studies expand by embracing and encouraging greater connections with areas such as medicine, social work, and public health.

Notes

1. I am focusing specifically on folklore studies in the United States because research in folklore and disability varies among countries. For example, there is a vibrant scholarly and activist tradition focusing on folklore and disability on the continent of Africa, though there is a great deal of inconsistency among countries on the continent. There are several African journals, such as the African Journal of Disability, the Southern African Journal for Folklore Studies, the Journal of Social Issues in Non-Communicable Conditions and Disability, and the African Disability Rights Yearbook, that routinely publish articles approaching disability from a wide range of disciplines, including folklore. In addition to these, there are numerous non-academic publications addressing disability and culture in different parts of Africa. A number of international journals, such as the Review of Disability Studies and the Disability Studies Quarterly also publish articles focusing on disability and folklore in different parts of the world.
2. When I first began research in disability studies around 2010 after being diagnosed as autistic, it radically changed the trajectory of my work. By that point, I had been teaching courses in folklore for almost 30 years, including a variety of courses in folklore studies, film studies, literature, and creative writing. My research in DS led me to re-envision courses that I had already been teaching as well as to create new ones. I offered courses at the undergraduate and graduate levels such as “Folklore and Disability,” “Disability and Visual Culture,” “Disability and Creative Nonfiction,” and my course on “Folklore and Film” became “Folklore, Film, and Disability.” In all of these courses, some of my primary objectives were to introduce students to DS and to have them come away with knowledge about some of the fundamental theoretical ideas from the field. I wanted them to understand the impact that ableism has on the disabled; to have a better appreciation of whatever the artistic forms under consideration might be (folklore, film, etc.); to be introduced to some key ideological ideas within other fields such as folklore studies, and to how the multiple fields under consideration might complement each other; to appreciate ways in which different artistic forms can perpetuate, critique, or resist ableist perspectives; to better understand the life experiences of disabled people; and to be nudged toward being either allies of disabled people, or if they were disabled themselves, to become more empowered. In the interest of transparency, I have approached editing this special issue with much the same focus.

3. Interestingly, Goffman’s work evolved out of dramaturgy, a perspective in the field of sociology, and reference to his theory “sets the stage” for employing theories developed in other fields (such as DS) to the study of folklore and disability. A prolific and influential scholar, he also published works that focused on interactional rituals, asylums, and gender (See Goffman 1956, 1961, 1963).

4. Blank and Kitta allude to this in commenting on how uncomfortable it must be for folklorists to engage with the issues of illnesses and disabilities. See “Introduction,” in which they write: “Perhaps scholars have been reluctant to work with disability because the space that they occupy is outside of the researcher’s comfort zone or too close to home (Blank and Kitta 2015b:8).

5. Blank and Kitta consider this issue in discussing the complexity of writing about disabled people (2015b:4). They note the potential for folklorists to cast disabled people in the role of victims when writing about them, a tendency that Shuman has referred to as “strategic romanticism” (Shuman 2011:167).

6. Consider that the Americans with Disabilities Act, intended to prevent discrimination against disabled people, was only signed a few decades ago, in 1990. Like the Civil Rights Act of 1964, and others like it, the Americans with Disabilities Act has continued to meet with resistance and is often ignored by employers and institutions.

7. The ideology of “ability” is not necessarily the same as the colloquial use of the term. However, the term can be off-putting for those in DS and to disabled people in general, because it has sometimes been used in order to avoid the term “disability.” Such avoidance tends to reinforce negative stigmas and to erase the histories and lived experiences of disabled people. For example, some organizations have renamed “Disability Week” as “Ability Week.”

8. In “Sighting Sound/Sounding Sight: The ‘Violence’ of Deaf-Hearing Communications,” Heidi Rose and Andrew Smith write: “Symbolic violence may be direct and personal, such as an explicit threat imposed by one person on another, or it may be indirect and impersonal, as when embedded in institutional relations of power” (2000:372). See also Bourdieu (1991).

9. For example, such colloquialisms as “that’s crazy,” “insane,” “lame,” “spaz,” “bananas,” “tone deaf,” “schizo,” “imbecile,” or proverbs, such as “to turn a deaf ear,” “the blind leading the blind,” “seeing is believing,” and “to dumb things down” are woven into the fabric of everyday speech.

10. In the 1930s more than half the states in the United States adopted laws that enforced sterilizations and over 30,000 people were sterilized. In the case of Buck v. Bell, Supreme Court Justice Oliver Wendell Holmes, Jr., claimed: “It is better for all the world, if instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind” (Lombardo ([2008] 2022:xi). It wasn’t until the mid-fifties and much later that professional organizations dropped the term “Eugenics” from their names. For example, in 1972 the American Eugenics Society became the Society for the Study of Social Biology, and their publication, the Eugenics Quarterly became Social Biology. Although the eugenics movement (that incidentally, like similar movements, overlapped with racist agendas) lost steam in the 1940s, their philosophies and practices still

11. Between 1867 and 1974 a number of US cities passed laws that outlawed the public appearance of people who were, in the language of the Chicago City Code 1881, “diseased, maimed, mutilated, or in any way deformed, so as to be an unsightly or disgusting object” (Schweik 2009:86).

12. One of the most illustrative narratives is that of “Eyeth,” which is popular in American Deaf folklore. In the story, a child attending a school for Deaf children is crying because they don’t want to go home to their nonsigning family. Their teacher tells them about a planet called “Eyeth” where they would be more at home. The child eventually becomes an astronaut and journeys to the planet of Eyeth, where everyone signs. As a teacher themselves on Eyeth, teaching hearing and speaking students, they encounter a student who is crying because they don’t want to go home to a family where everyone is Deaf. The teacher then tells them about a faraway planet called “Earth” where they would fit in and would be happier (Rose and Smith 2000:369).


14. While there is a proliferation of films portraying disabled people through ableist lenses, there are many cinematic and ethnographic films that more accurately reflect the life experiences, pride, and beauty of disability, with some of them sparking controversy. A few of these include: The House Is Black, directed by Forugh Farrokhzad (1963); Vital Signs: Crip Culture Talks Back, directed by David Mitchell and Sharon Synder (1995); Freaks, directed by Tod Browning (1932); Crip Camp: A Disability Revolution, directed by Nicole Newman and Jim LeBrecht (2020); and Lives Worth Living: The Great Fight for Disability Rights, directed by Eric Neudel (2011).

15. Norden’s schema for disabled characters in visual narratives include the demonic cripple, the obsessive avenger, the sweet innocent, the charity cripple, and the saintly sage (Norden 1994).


17. Some of these include Jean Bergey, Amy Shuman, Olivia Caldeira, Phyllis M. May-Machunda, and Andrea Kitta.


19. A number of factors account for the variations in statistical data about the numbers of disabled people nationally or globally. One is that different organizations have different ways of collecting data and sometimes have different criteria for what counts as a disability. Another has to do with how disabled people are identified, for example, the extent to which surveys depend on self-reporting or what kinds of data bases are used.

20. To cite my personal experience, I am currently an affiliate faculty at the Thompson Center for Autism and Neurological Disorders in Columbia, Missouri. Other faculty, and graduate students trained through the center, are from diverse fields such as occupational and physical therapy, social work, speech pathology, clinical psychology, psychiatry, and medicine. They are very interested in writings from the humanities because such work expands their understanding of autism and the autistic people with whom they work. One of my roles is to offer perspectives that those trained in more medically oriented fields may not otherwise think about. Furthermore, besides those graduate students who have gone on to have career jobs in academia, I have had many undergraduate and graduate students who have gone into careers in diverse fields such as law, medicine, social work, event planning, architecture, occupational therapy, and counseling, and whose perspectives were profoundly changed by taking courses in folklore and disability, ultimately affecting their considerations when encountering disabled people in their professional and personal lives.

21. The idea for this special issue grew out of the 2022 webinar sponsored by the Fellows of the American Folklore Society entitled “Interrogating the Normal: Folkloristic Engagements with Disability.”
panelists included Amy Shuman, who moderated and provided plain language summaries of presentations; Nora Ellen Groce; Phyllis M. May-Machunda; and me.

22. “Intersectionality” is a common term in DS. At the level of disability and experience, it refers to multiple, overlapping identities, such as disabled and Black; disabled and queer; or disabled, Black, and queer. On the level of scholarly or other forms of discourse, it refers to multiple, intersecting, disciplinary perspectives (Grenshaw 1991).

23. There are indications that the American Folklore Society (AFS) has become increasingly concerned with many of these issues. For example, the Executive Board has considered ways in which to make conferences more accessible, and there has been a marked increase in the number of disability-related panels at the annual AFS conference meetings.


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