Diagnosing folklore: Perspectives on disability, health, and trauma is an exploration of disability, illness and trauma from within an ethnographic folk studies tradition. Different contexts of meaning making about disability, illness and trauma are examined through case studies and theoretical explorations about how the boundaries between normalcy and stigma are negotiated and contested in popular narratives, by ordinary people.

In the introduction, “The Anatomy of ethnography: Diagnosing folkloristics and the conceptualization of disability”, Blank and Kitta situate the volume within a tradition of folk studies, based on ethnographic research and analysis and sharing their same commitment to “give those who do not have a voice a chance to represent themselves” (p.5), as well as in disability studies’ explicit goals “to critique the sympathetic and the celebratory” (p.24) and to create scholarship that can be used towards advocating for change. The diverse narratives presented in this volume serve to render the full complexity of experiences and reactions to disability, illness and trauma. Blank and Kitta also stress that stigma’s role in shaping folklore about disability, illness and health is crucial in all the articles in this edited volume. Stigma is defined as the result of the process by which people’s self-narratives about their lived-experiences with disability, illness, and trauma are discredited and delegitimized by the medical establishment and its practitioners as well as cultural and social beliefs. This collection, therefore, pushes back against biomedical attempts to create a universal narrative about these aspects of human experience.
Each article offers instances of resistance to this glossing over of the complicated relationships we entertain with our bodies and selves as limiting and enabling our future actions and existence within our communities and the wider world: the perceptions of participants and their families in Special Olympics clashing with accounts of segregation by disability rights activists, the stories of resilience of survivors of Hurricane Katrina challenging accounts given by the media, and the therapeutic use of plants and the links made between emotions, stress, and traumatic experiences by Latinas/os in the treatment and understanding of diabetes are some examples. Concurrently, the volume presents layered critiques of how beliefs about disability, illness, and trauma emerge in different areas of popular culture, inseparable from dominant stereotypes about race, gender, and ability. Such is the case, for example, in the analysis of the “insanity coda” (p.159) which emerges in contemporary legends as ways of making mental illness visible on the physical/social body as abnormality that can be differentiated from sanity.

The articles also offer points of contact between stigmatizing narratives about disability and illness and the resistant knowledge-construction of disabled and ill people themselves. They bring to the fore both the tensions existing between the two, but also the personal strain this dissonance creates for disabled and ill people in their personal lives and interactions with others who may disbelieve their accounts as inconsistent with the “truth” about being disabled or ill. The narratives of familial predisposition to diabetes by Appalachians, for example, counter popular belief about their culture as inherently unhealthy and uneducated, and of diabetes as the result of individual life choices. Similarly, the vlogging practices of people who have bipolar disorder on YouTube present their experiences as valid and even privileged forms of knowledge.

Moreover, the articles provide an examination of how stigmatizing narratives are sometimes both imposed from without cultural communities and within, such as in the case in
the conception of some autistic characteristics as acceptable behaviour in Javanese culture, while
the label itself is viewed as shameful. These acts of resistance by disabled and ill people against
popular conceptions at time take the form of refusal to comply with ableist expectations: This
situation is explored, for example, in the practice of “falling out of performance” (p.215) by
veterans who evade the expected performance of narratives of trauma as a strategy to evade the
limited roles imposed on them by society. The refusal to uphold the mainstream view of
disability and illness as undesirable can also emerge as an eroticization of disabled, ill, and
vulnerable bodies of patients, and their relationships with medical procedures and professionals.
The re-signifying of disability, illness and trauma as existing within an erotic economy
transforms their meaning for participants, many of whom are disabled people and/or medical
practitioners.

Similarly, healing practices represent and re-present aspects of ourselves that are mostly
absent when dealing with medical institutions and professionals: our beings as belonging to
communities and in relations with many others with whom we share emotional and spiritual ties.
The exploration of a community of women healers in the Midwest explores alternative
understanding of healing as a communal and spiritual practice, separate but not divorced, from
Western medicine, but rather as adding to it. This volume thus presents articles that explore the
fraught relationships with health, moral value, and meaning that we are thrust into when we are
ill, disabled, or have traumatic experiences.

The book is divided into three investigative areas: the exploration of discursive
constructions of disability and stigma in “Part One: Disability, ethnography and the stigmatized
vernacular”; the investigation of practices of meaning-making about disability and health, as well
as how stigma is negotiated, in particular cultural and ethnic communities in “Part Two: Folk Knowledge, belief, and treatment in regional and ethnic health praxis”; and “Part Three: The performance of mental illness, stigma, and trauma” explores how disability is performed in different cultural contexts and communities.

The concept of the “stigmatized vernacular”, referenced by a few of the authors in the volume, is introduced in the first article, “Disability, narrative normativity, and the stigmatized vernacular of communicative (in)competence”, by Amy Shuman. She defines it as “the process of managing” how value is assigned, claimed, and denied in social interactions” by people with potential stigmatized identities (p.25). “Vernacular” here refers to language and to strategies and performances that are contextually located. Shuman explores the concept of communicative competence, or rather incompetence, of certain subjects perceived as failing at constructing a coherent narrative in order to challenge the notion of “narrative normativity” that underlays it (p.32). Instead she demonstrates that “communicative competence” is a normative system that obscures the reality of narrative as co-constructed between participants.

The Second article, Olivia Caldeira’s “Exploring esoteric and exoteric definitions of disability: Inclusion, segregation, and kinship in a Special Olympics group”, explores how the politics of inclusion versus segregation in the Special Olympics can disregard the significance of the experiences of participants. Caldeira disturbs the dichotomy of inclusion as desirable and segregation as oppressive, proposing instead, that we pay attention to the ways in which segregated spaces such as Special Olympics groups contribute to eradicating stigma, as well as to the opinions of those who are part of such communities.

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1 Term developed by Amy Shuman and Diane Goldstein (also with an article in this volume) in the journal of Folklore Research, Vol. 49, No. 2, The Stigmatized Vernacular (May – August 2012).
Sheila Bock and Kate Parker Horigan, in “Invoking the relative: A new perspective on family lore in stigmatized communities”, analyze how the concept of “family” is mobilized by individuals to avoid stigma in instances of community trauma, such as Hurricane Katrina and the high rate of type 2 diabetes in the Appalachian community. Bock and Horigan notably examine how African-Americans who stayed behind were constructed as deserving of their misery because they did not evacuate, even more so than those who evacuated. This re-framing of the moral value of responding to collective trauma illuminates how stigma is mobilized to marginalize certain communities.

The second part opens with an article by Michael Owen Jones: “Latina/o local knowledge about diabetes: Emotional triggers, plant treatment and food symbolism”. In it, the cultural logic of knowledge about diabetes’ cause and treatment are examined. Jones demonstrate that much of this local knowledge is echoed by recent medical and clinical studies that have determined that emotions and stressful events play a role in the development of diabetes and that plant-based therapies are effective in its treatment. He further advocates for developing health strategies that reflect the local understanding of diabetes as psychological, cultural, and social as a future necessary step.

Similarly, Annie Tucker’s article, “Interpreting and treating autism in Javanese Indonesia: Listening to folk perspectives on development difference and inclusion”, also advocates for the valuing of local knowledge about health and disability in devising more effective health care strategies.

In “‘Heal thyself’: Holistic women healers in Middle America”, Elaine J. Lawless explores how a specific community, that of women energy healers, contributes to both challenging and enhancing medical version of what constitutes treatment and cure.
“[H]ealing…does not necessarily mean being ‘cured’” (p.147), she reports one of her informants saying, a perspective medical practitioners need to hear, especially when dealing with those chronically sick and in pain. Apart from being a substantial examination of alternative healing practices, Lawless’ article also makes an important methodological contribution to how researchers should research communities not as external observers, but as participating members: “that we need to not only read over the shoulders of our participants, but also read alongside them”, and even more, “we need to ‘read with’ our participants” (p.139).

In the last part of the book, we are confronted with specific performances of disability, mental illness, and trauma. Diane E. Goldstein’s “Deranged psychopaths and victims who go insane: Visibility and invisibility in the depictions of mental health and illness in contemporary legends”, examines how contemporary legends reproduce tropes about mental illness as a result of traumatic circumstances or as a marker of dangerous non-normativity that follow gender lines: women who go insane are thereby made invisible by their “madness”, while men are perceived as “dangerously insane” and hypervisible.

Both Darcy Holtgrave’s article, “Broadcasting the stigmatized self: Positioning functions of the YouTube vlogs on Bipolar disorder”, and London Brickley’s “Tales from the operating theater: Medical fetishism and the taboo performativity power of erotic medical play” contribute to a transgressive rejection of stigma by those who are part of stigmatized communities. Holtgrave examines how vloggers who identify as bipolar position themselves as authoritative sources of knowledge by exposing their lives via YouTube videos. In so doing, not only do they actively reject their identity as stigmatized, but they also contribute to creating spaces where others can also do so as well as producing a discourse that challenges the legitimacy of stigma itself. Brickley’s article, for its part, explores the world of medical fetishists who eroticize the
medical-patient relationship. Brickley demonstrate that this world is imbedded in social and cultural contexts and emerges from them. Further, participants are presented as often already being from medical communities, either as patients or practitioners.

Finally, but not by any means least, Kristina Willsey’s article about the intentionally disruptive narrative performance by veterans with PTSD, “Falling out of performance: Pragmatic breakdown in veteran’s storytelling”, presents veterans as claiming agency over how their narratives of trauma can be understood. She demonstrates that veterans’ narrative strategies in controlling their stories via seemingly incoherent narratives affords them control over how these are assigned meaning in society, despite still being expected to follow accepted tropes when dealings with medical practitioners and government administrators. Their disruptions are often seen as a failure in communication and a proof of trauma, whereas Willsley determines they serve deeper functions: challenging that individual soldiers are responsible for the violence of war and instead focusing it on government decisions and, “as a proxy for the healing of a national audience” (p.229).

This volume demonstrates that the narratives of people with stigmatized identities, their strategies for managing stigma, challenging it, resisting it, is a collective process of re-valuation, and the exploration of these processes benefits whole communities and numerous fields of academic research. The articles in this volume thus exceed the field of folklore studies and critical disability studies and would, and should, be of interest to policy makers, health care practitioners, as well as patients, disabled, chronically ill and sick people whose lives continue to be affected by stigma and ableist beliefs.